

Delaware Journal of Public Health

January 2016
Volume 2 | Issue 1

a publication of the Delaware Academy of Medicine / Delaware Public Health Association

www.delamed.org | www.delawarepha.org

In this issue

Calendar of Events	3
A Message from the Editor and Executive Director	4
Welcome from this issue's Guest Editor	5
Interview with Susan Del Pesco, Esq.	8
An Interview with Dr. John Goodill	10
The Importance of Advance Health Planning.....	12
The Increasing Importance of Advance Care Planning	16
A Promise to Auntie Bini: Lessons From a 'Work Around' and the Value of DMOST	18
Impact of DMOST on Hospice and End-of-Life Care	22
The DPH Bulletin	24
Delaware Medical Orders for Scope of Treatment Act: Keeping Control of Treatment Decisions.....	26
The Evolution of Hospice Care: Expanding Access with the Concurrent Care for Children Provision.....	28
Glossary of Terms.....	34
Delaware Register of Regulations.....	40
'State of Public Health 2016' with CDC Director Tom Frieden	48
From the History and Archives Collection	50



COVER

The discussion about End of Life is exceedingly complex, replete with countless acronyms and terms which are sometimes interchangeable, but usually

very specific in their meaning. This word cloud represents many of the words, abbreviations, and terms that are part of this issue. Please see pages 34-37 for a glossary of terms.

The Delaware Journal of Public Health (DJPH), first published in 2015, is the official journal of the Delaware Academy of Medicine / Delaware Public Health Association (Academy/DPHA).

Submissions: Contributions of original unpublished research, social science analysis, scholarly essays, critical commentaries, departments, and letters to the editor are welcome. Questions? Write chealy@delamed.org or call Liz Healy at 302-733-3989.

Advertising: Please write to chealy@delamed.org or call 302-733-3989 for other advertising opportunities. Ask about special exhibit packages and sponsorships. Acceptance of advertising by the Journal does not imply endorsement of products.

Copyright: Copyright © 2016 by the Delaware Public Health Association. Opinions expressed by authors of articles summarized, quoted, or published in full in this journal represent only the opinions of

the authors and do not necessarily reflect the official policy of the Delaware Public Health Association or the institution with which the author(s) is (are) affiliated, unless so specified.

Any report, article, or paper prepared by employees of the U.S. government as part of their official duties is, under Copyright Act, a "work of United States Government" for which copyright protection under Title 17 of the U.S. Code is not available. However, the journal format is copyrighted and pages may not be photocopied, except in limited quantities, or posted online, without permission of the Academy/DPHA. Copying done for other than personal or internal reference use—such as copying for general distribution, for advertising or promotional purposes, for creating new collective works, or for resale—without the expressed permission of the Academy/DPHA is prohibited. Requests for special permission should be sent to chealy@delamed.org.

Delaware Academy of Medicine

Board of Directors:

OFFICERS

Arun V. Malhotra M.D.,
President

Daniel Meara, M.D., D.M.D.,
President-Elect

Kathleen S. Matt, Ph.D.,
Vice President

Victor L. Gregory, D.M.D.,
Treasurer

Omar A. Khan, M.D., M.H.S.,
Secretary

Kathleen W. McNicholas, M.D., J.D.,
Immediate Past President

Timothy E. Gibbs, MPH, NPMc,
Executive Director, Ex-officio

DIRECTORS

Cynthia A. Gabrielli, D.O.

Eileen Grena-Piretti,
R.N., B.S.N., J.D.

Joseph F. Kestner, Jr., M.D.

Brian W. Little, M.D., Ph.D.

John Piper, M.D.

Albert A. Rizzo, M.D.

S. John Swanson, M.D.

EMERITUS

Robert B. Flinn, M.D.

Barry S. Kayne, D.D.S.

Leslie W. Whitney, M.D.

Delaware Public Health Association

Advisory Council:

Omar Khan, M.D., M.H.S.,
President

Timothy E. Gibbs, M.P.H.,
Executive Director

Louis E. Bartoshesky, M.D., M.P.H.

Richard J. Derman, M.D., M.P.H.

Gerard Gallucci, M.D., M.S.H.

Richard E. Killingsworth, M.P.H.

Erin K. Knight, Ph.D., M.P.H.

Melissa K. Melby, Ph.D.

Mia A. Papas, Ph.D.

Karyl T. Rattay, M.D., M.S.

Margot L. Savoy, M.D., M.P.H.

Paul R. Silverman, DrPH

Rob A. Simmons, DrPH

William J. Swiatek, M.A., A.I.C.P.

Delaware Journal of Public Health

Omar Khan, M.D., M.H.S., F.A.A.F.P.

Editor-in-Chief

okhan@christianacare.org

Kathleen W. McNicholas, M.D., J.D.

Guest Editor

kmcnicholas@christianacare.org

Liz Healy

Deputy Editor

chealy@delamed.org

Christian Derr

Image Director

info@christianderr.com



UPCOMING EVENTS IN DELAWARE

February 4, 2016

MGR: The Global Tobacco Epidemic | Christiana Care Health Systems Global Health Residency Program

February 18, 2016

Physical Diagnosis | Christiana Care Health Systems Global Health Residency Program

February 13, 2016

2016 American College of Physicians Delaware Chapter Annual Meeting – www.delamed.org/pdfs/ACP2016.pdf

March 4, 2016

27th Annual Update in Cardiology | Christiana Care Health System

March 10, 2016

Focus on Hypertension

Thursday, March 10, 2016

Delaware Academy of Family Physicians 14th Annual Sports Medicine Symposium

March 17, 2016

Refugee Health

March 18, 2016

Delaware Nurses Association Spring Conference 2016

May 24, 2016

PrEP Education Conference | Delaware HIV Consortium

April 2, 2016

Lori's Hands 2nd Annual Picnic Event
Register at www.lorishands.org

April 4-10, 2016

National Public Health Week

April 6, 2016

Tropical Medicine | Christiana Care Health Systems Global Health Residency Program

April 8, 2016

Neurovascular Symposium | Christiana Care Health System

Saturday, April 9, 2016

Delaware Academy of Family Physicians Scientific Assembly

**April 21, 2016 - Delaware Academy of Medicine/
Delaware Public Health Association
86th Annual Meeting**

For general inquiries about the Delaware Journal of Public Health or possible contributions for upcoming issues, please contact Liz Healy

Membership Categories include:

Individual:

Year 1 discount: 75% off \$25, **Year 2 discount:** 50% off \$50, **Year 3 discount:** 25% off \$75, Year 4 and each year after \$99, **6 Year bundled discount rate:** \$315 for a six year membership. Save \$132. **Retired:** \$25 per year. **Student:** \$10 per year.

Apply online at delawarepha.org or email elenz@delamed.org (Liz Lenz) or call **302-733-3952** for more information.

Similar to the APHA, sections serve as the primary professional units of the Association and conduct activities that promote the mission and fulfill the goals of the Academy/DPHA. Sections create a variety of opportunities for member involvement, thus making the the Academy/DPHA experience richer for individuals who have the opportunity to attend and choose to interact with their primary Sections.



DELAWARE
ACADEMY of
MEDICINE

DPHA
DELAWARE PUBLIC HEALTH ASSOCIATION

Delaware Academy of Medicine / DPHA

4765 Oglethorpe-Stanton Road
Suite L10
Newark, DE 19713

www.delamed.org | www.delawarepha.org

Follow Us:



The Delaware Academy of Medicine is a private, nonprofit organization founded in 1930. Our mission is to enhance the well being of our community through medical education and the promotion of public health. Our educational initiatives span the spectrum from consumer health education to continuing medical education conferences and symposia.

The Delaware Public Health Association was officially reborn at the 141st Annual Meeting of the American Public Health Association (APHA) held in Boston, MA in November, 2013. At this meeting, affiliation of the DPHA was transferred to the Delaware Academy of Medicine officially on November 5, 2013 by action of the APHA Governing Council. The Delaware Academy of Medicine, who's mission statement is "to promote the well-being of our community through education and the promotion of public health," is honored to take on this responsibility in the First State.

“The end-of-life deserves the same level of meaningful research and study, legal and ethical consideration, viewed through the lens of access and equity.”



Omar A. Khan, M.D., M.H.S.
President
Delaware Public Health Association



Timothy E. Gibbs, M.P.H.
Executive Director
Delaware Academy of Medicine and
the Delaware Public Health Association

Dear Colleague,

2016 will, undoubtedly, be an interesting year for public health internationally, nationally, regionally, and locally in Delaware. Internationally, refugee health due to the Syrian crisis is a massive concern, and is composed of multiple subsets of public health issues, including mental health, poverty, discrimination, and unemployment. Nationally, the US health system has become accustomed to Obamacare and gears up for new changes which will affect all health systems. The CDC Influenza Report provides some positive news- thus far a less deadly flu season than we experienced last year. With the vast majority of circulating viruses being similar to the vaccine virus components for this season, it is imperative (and beneficial!) to get vaccinated immediately. In Delaware, we continue to face the challenges of chronic diseases such as diabetes and obesity, and in the City of Wilmington, alarming rates of gun-related violence and infant mortality. Our work has never been more important or more necessary.

Here in Delaware, we are preparing for collaborative educational activities around hypertension, with the Focus on Hypertension Conference (March 10th); lay education through the Delaware Mini-Medical School running in March and April; and HIV/AIDS and the Pre-Exposure Prophylaxis (PrEP) Education Conference (May 24th), and our own annual meeting on Friday April 22nd at the DuPont Country Club. The invited speaker is United States Surgeon General, Vice Admiral Vivek Murthy, MD, MBA- stay tuned for more!

We are also setting the stage for National Public Health Week, which runs April 4 – 10, and we look forward to a return to the STAR Campus to collaborate with the activities of the Delaware Health Sciences Alliance and the University of Delaware. During that week we'll also be conducting our first 5k Walk/Run – details to follow. See our complete calendar of events on page 3.

Exciting new education activities are in the works, thanks to your DPHA Advisory Council. These include a Public Health Grand Rounds series, which will engage our partners across the state for relevant, interesting topics which you will not want to miss.

The Academy/DPHA, in partnership with the Delaware Chapter of the American Planning Association, has been awarded funding from the Centers for Disease Control and Prevention to undertake an important effort in Kent County, Delaware – and you can read more about that on page 15.

In this edition of the DJPH, guest edited by Dr. Kathleen McNicholas, we address end-of-life issues and the new Delaware Medical Orders for Scope of Treatment (DMOST) Regulations and form. Virtually every public health activity seeks to improve the circumstances we live in, leading to a higher quality of life free from the burden of disease and premature death. The end of life deserves the same level of meaningful research and study, legal, and ethical consideration, viewed through the lens of access and equity. We hope you will find this issue thought provoking and informative.

Our March edition of the *Delaware Journal of Public Health* will be predominately focused on sexually transmitted infections, which while remaining largely preventable, still remain a significant public health issue, resulting in high costs and tremendous burdens. Other topics to be covered in the March edition include the rapidly spreading Zika virus, which is attracting the attention of public health officials globally.

As always, we would be glad to hear from you, our valued members. Drop by, or drop us a line!

Yours in health,

Omar Khan, M.D., M.H.S., F.A.A.F.P.
President

Timothy Gibbs, M.P.H.
Executive Director

LATE BREAKING NEWS
The January 19, 2016 edition of the *Journal of the American Medical Association* highlights "Death, Dying and End of Life" [click here](#) to view the table of contents



About this Issue

On behalf of the Delaware Academy of Medicine and the Delaware Public Health Association, I am honored to act in the capacity as guest editor for this edition of the *Delaware Journal of Public Health*. This edition focuses on end-of-life issues and Delaware Medical Orders for Scope of Treatment (DMOST), and while those of us working in medicine and healthcare fully appreciate how fragile life is, and how inevitable end-of-life issues are, taking this dialogue into the realm of public health is a new conversation.

In the United States, people live an average 30 years longer now than they did 100 years ago due to advances in public health and medicine. This success has created a new public health environment. While death occurs at a much later age, it is often associated with protracted (and therefore, expensive) illnesses. End-of-life care has three components that favor public health intervention: high burden, major impact, and significant potential for preventing suffering associated with illnesses. This last point is addressed through pain and palliative care management. In addition, serious end-of-life illness in a loved one can create major and unexpected life changes for family members including depression, secondary morbidity and mortality, and major financial consequences, including loss of primary household income and life savings.

You may still ask yourself, ‘But why and how does public health play a role?’ Historically, public health has led the way in population data collection and analysis. Public health professionals are trained in the sciences of biostatistics and epidemiology, and both are critical areas of expertise for best addressing issues such as those posed by end-of-life scenarios. Secondly, public health excels at providing health information and health literacy programs for diverse lay populations with a sensitivity and consideration to culture, education, age, and gender. Public health is a natural partner to healthcare systems and as a result public health is on the leading edge of advocating for both equality and equity in all healthcare transactions. Finally, public health understands the benefit of “health in all policies.” This means that any and all policy decisions made at local, state, national, and international levels need to have professionals viewing the policy and regulation development for potential positive and negative impacts on the community the policy will be applied to.

The Delaware Academy of Medicine / Delaware Public Health Association sits squarely at the intersection of medicine and public health on end-of-life issues. This is similar to the position of many of our partners in Delaware who have worked tirelessly to see the passage of the Delaware Medical Orders for Scope of Treatment (DMOST) legislation. As we move into the implementation and training phase with DMOST through the Goals of Care Delaware program, we’ll be leveraging all five of the above mentioned attributes.

As Nathan Kottkamp, Esq., chair of the National Healthcare Decisions Day Initiative states: “Several recent events (domestically and internationally) serve as dramatic reminders of the randomness of life, which makes it all the more important that we all plan ahead regardless of our age or current health status—remember, **‘It always seems too early, until it’s too late.’**” Thus, where appropriate, if you find yourself in discussions about recent tragedies, please consider weaving advance care planning into the discussion. You can direct others to the free advance care planning resources and/or those we have assembled at www.nhdd.org.

We hope you will find this edition of the DJPH insightful and thought provoking.

Kathleen W. McNicholas, M.D., J.D.

Immediate Past President, Delaware Academy of Medicine / Delaware Public Health Association



Kathleen W. McNicholas, M.D., J.D.,
Guest Editor, January 2016

Dr. McNicholas is a past president of the Academy of Medicine. One of the many programs she championed during her presidency and we continue today is the central topic of this edition. Dr. McNicholas received her medical degree from Thomas Jefferson Medical College and her law degree from Widener Law School. See her own personal family story on page 18.



January 4, 2016

Dear Reader,

This issue of the Delaware Journal of Public Health is dedicated to the new Delaware Medical Orders for Scope of Treatment (DMOST) law. The DMOST law would not have happened without the close collaboration and dedication of Delawareans from all stakeholder perspectives. Doctors, nurses, lawyers, administrators, and state employees worked together on the law and subsequent regulations to make the implementation of DMOST strong and effective.

Knowing what patients want at the end of their lives has proven to be the challenge of the 21st century because only about 25 percent of the population has an Advance Health-Care Directive (AHCD). When there is an AHCD available, it was generally prepared years in advance and does not speak to the specific issues of a patient's current medical condition.

The DMOST law seeks to fill that gap. It provides for a process to determine personal preferences, and to record those preferences on a standardized form. It can be used to allow a natural death for someone at the end of life. It can also be used to direct medical providers to try all measures to sustain life. It allows an individual's preferences to be known and ordered because the DMOST form is a medical order that is portable and must be honored by Delaware health care providers in all settings. Thus, it can be followed by EMS at home or in the community or by a medical provider in a hospital.

The DMOST form is consistent with the work of the Department of Health and Social Services (DHSS). At DHSS, we support vulnerable populations and their caregivers, oversee the Delaware Emergency Medical Services program, and have been working to transform health care so that patient care is coordinated across providers and people can live in the least restrictive environment of their choosing. The DMOST form is an important, voluntary tool that can guide and memorialize end-of-life conversations and ensure that each individual gets the care and treatment they desire, wherever they are.

Thank you for the care you provide to Delawareans.

Sincerely,

Handwritten signature of Rita M. Landgraf in blue ink.

Rita M. Landgraf, Cabinet Secretary
Department of Health & Social Services

Handwritten signature of Dr. Karyl Rattay in blue ink.

Dr. Karyl Rattay, Director
Division of Public Health



27th Annual
Update in Cardiology

**Continuing Physician
Professional
Development/CME**



**CHRISTIANA CARE
HEALTH SYSTEM**

Topics covered include:

- **Structural heart interventions.**
New TAVR devices: Impact on practice patterns.
- **The Placebo effect –**
why is it so important to understand in contemporary cardiovascular medicine?
- **Health care in the future:**
What will change and what will stay the same?
- **Two new drug advances introduced in 2015:**
Neprilysin Inhibitors:
Dramatic advance in CHF Management
PCSK9 Inhibitors:
A new class of drugs for cardiology, injectable and very effective.
- **Disparities in cardiovascular health care delivery.**
What are they?
How can we reduce them?

This innovative and proactive presentation will explore recent developments in evidence-based cardiovascular medicine.

Friday, March 4, 2016

7:55 a.m. – 4 p.m.

(Registration and exhibits begin at 7:30 a.m.)

John H. Ammon

Medical Education Center

Christiana Hospital Campus, Newark, DE

- Fee:** Christiana Care Health System employees – \$55 in advance (\$75 “day of” registration, if seating permits)
Non-Christiana Care employees – \$75 in advance (\$95 “day of” registration, if seating permits)
Full-time students – \$20
There is no charge for Christiana Care residents and fellows to attend. (Registration is required.)

Registration Deadline: February 25, 2016.

Pre-registration required. Register online:

<https://cchs.cloud-cme.com/cardiology2016>

Questions: Email rpugh@christianacare.org.

Q & A

Interview with Susan Del Pesco, Esq. | *by Liz Healy*



Susan Del Pesco, Esq.

Judge Susan Del Pesco was the first woman elected as President of the Delaware Bar Association and the first women appointed to the Delaware Superior Court. She championed the opening of a Women's Work Release and Treatment Center, the creation of a chapel at Baylor Women's Correctional Institute (BWCI), and has led two book drives for residents at BWCI. Judge Del Pesco led an effort to identify and raise awareness about issues of gender-bias in the courts, as well as initiating the Superior Court's Project Rightful Owner, which is an effort to assist persons whose property has been sold at Sheriff's sale to claim excess funds remaining after all mortgages and liens were paid. Finally, she has played an active role in the creation and enactment of the DMOST statute.

LH: Can you tell me a bit about your background and how you first gained an interest in end-of-life issues?

SDP: I was on the Superior Court for 20 years, retiring in 2008. Shortly after I retired, I took a position in the Department of Health and Social Services as the Director of the Division of Long Term Care Residents Protection. Through that position, I became aware of many issues affecting people living in long term care facilities. One of those issues was how best to understand and respect each resident's end-of-life choices.

LH: Have there been any individuals or any specific

experiences that may have led you to become more passionate about end-of-life decisions and medical orders?

SDP: There was a conference in 2009 at the Delaware Law School which I attended. Pat Bomba, a very effective advocate from New York, spoke at the conference about end-of-life medical orders, and how they differ from and are better than advance directives. That was my first introduction to the concept. It was directly relevant to the work I was doing, and of personal interest as a senior! Later, I became involved in the effort to have an end-of-life medical order available in Delaware—the effort that ended with the enactment of DMOST, the Delaware Medical Orders for Scope of Treatment.

LH: What do you think makes end-of-life decisions so complex, and this process so challenging?

SDP: Like many things, once people understand the goal and the process, it is not complex, and the biggest challenge has been overcome with the enactment of the statute.

DMOST is about a conversation. The conversation takes place at a time when the patient has reached that time when his or her provider would not be surprised if he or she died within the year. That timing is critical as it provides the best context for the decisions. The patient's actual health challenges are discussed so the decisions are made in the context of that patient's prognosis. The decisions are then recorded

on a prescribed form so that any health care provider will have easy access to clear directions. The form is portable, which means it travels with the patient to various care settings—hospital, nursing home, hospice, or home. And the law requires that providers give care as directed.

Health care providers who have had experience with end-of-life orders in their state say that having a process that invites people to participate in guided conversations so that each patient's desires can be known is a critical step forward. The patient's right to specify their end-of-life care has long been acknowledged by the law and medical ethics. The challenge has been providing a way to know those preferences.

Death is a very difficult subject for the patient, for families, and for care providers. That's why there have been so many times when family members are left struggling to make decisions, or there are situations where there are no available family members, so surrogates struggle to figure out what care a patient would have chosen.

If people, be they children, spouses, or legal agents, know end-of-life preferences, decision making is much easier on everybody. Conflict is avoided, and—most importantly—the patient's desires are respected.

LH: In your experience, have you seen any particularly impactful changes in processes or attitudes?

SDP: The baby boom generation is now getting to the age where this issue matters, and there are many, many of us. Thus, the need to provide a process for knowing end-of-life medical preferences has taken on a greater urgency.

Delaware's law allowing advance health care directives was a new idea when it was enacted in the 1990's, and it was an important first step. But advance directives have proven to provide little assistance in many circumstances because the decisions, made in a lawyer's office or elsewhere without medical input, sometimes were medically illogical—such as wanting CPR but not wanting ventilation. And, more importantly, those decisions, made out of the actual context of a patient's

condition and prognosis, often were stale—they no longer reflected the patient's preferences. The absence of a standardized form also made advance directives difficult to interpret, thereby limiting their utility. And, of course, an advance directive is just a piece of paper until it becomes a medical order. DMOST creates a medical order that is immediately actionable.

The most important thing is teaching patients that they are entitled to make decisions about their own care, and enabling medical providers to honor those decisions.

LH: What are your hopes for how these conversations will continue to be had with family members and loved ones?

SDP: My hope is that every person approaching the end of their life will have an opportunity to engage in a really meaningful conversation—more than once, if that is what they want—so that they can make informed decisions while they have the capacity to do so, with the comfort of knowing that those decisions will be respected.

There is reason to believe that's going to happen since CMS has recently authorized reimbursement for the conversations. Having the financial piece in place enables providers to allocate time so that trained personnel will be able to talk with the patients and, if desired, their family.

Certainly, a challenge lies ahead as many people need to be trained about the law, and how it is meant to work.

LH: How did you get involved with the DMOST statute?

SDP: Well, this began when the Academy of Medicine convened a group of interested parties in January of 2013. I was one of those people. I had just retired from the Division of Long Term Care, but was certainly interested in working on for the sake of everybody in the state of Delaware. A subgroup was created to draft the legislation. I had been involved in other legislative endeavors before so this was a good fit for me, along with a number of the other lawyers who participated in the effort.

LH: That leads into my next question, actually, what other projects or initiatives have you been involved in?

SDP: While with DHSS, and with the goal of protecting people—often seniors—from financial exploitation, I was involved in writing and enacting legislation which updated the Delaware durable personal power of attorney statute. Delaware's statute now conforms to best national practices.

LH: You have been quoted saying you feel end-of-life issues are intertwined with civil rights issues, can you expand upon that at all?

SDP: I actually learned that from an ACLU document. The ACLU describes end-of-life medical orders as a civil rights issue, and when one reflects on the fact that there is a legal and ethical obligation to respect people's end-of-life preferences, and at the same time plenty of evidence that many times such preferences are ignored, it is easy to agree with that statement. People have a right to make those decisions for themselves, but without a process for capturing that information, it was an empty promise.

LH: What are some of the things you would like our readers to take away from this issue?

SDP: I think the most important message is don't be afraid to talk about end-of-life issues when the time is appropriate. We have in our society an aversion to discussing death. People, including many physicians, are very uncomfortable talking about it, and yet, if there is no conversation, everything is more difficult when the time comes. Providing the DMOST process, talking at a time when it doesn't feel frightening, is a very healthy step forward.

I also would like your readers to know that without the leadership of Kathleen McNicholas MD, John Goodill, MD, and the Academy of Medicine in gathering like-minded people to draft and support DMOST, and the work of Secretary Rita Landgraf and Debbie Gottschalk, Esq. of DHSS in getting the legislation passed, DMOST would not soon be available. I offer them my thanks. ■

An Interview with Dr. John Goodill

by Liz Healy

LH: With the baby boom generation aging, and the increase in the elderly cohort in the United States, what do you think is on the horizon for healthcare and public health as a result of this demographic shift?

JG: I think much of the picture we are seeing is not a changing demographic, but an enlarging demographic of people who are living longer with a higher burden of illness; that's going to put stress on our healthcare system to take care of them in a different and better way. People are living longer with serious advanced illness that is non-curable and often progressive. We don't cure a lot of them, but we do help improve their quality of life, and help them live and enjoy the time that they have.

LH: How do you think individuals, as well as the healthcare system, and prepare for some of those challenges and inevitable stresses that lie ahead?

JG: I think that we have to pay attention to people's experience living with serious illness and what their needs are, and try to do the best to understand what's important to them- that's what advance care planning is all about. What is important to one person is not necessarily what is important to another, so this is a very personal, person-centered approach.

We also need to pay attention to meeting the non-medical needs of people with serious illness. For example, social services are becoming increasingly important, and delivering the support that these people need in the place where they are, so they don't have to be in the hospital. People don't want to be in the hospital, they want to be at home. We have to support people where they are, and that means fashioning the system to ensure this kind of work is appropriately

compensated. I think there's a lot of evidence that shows the right medical care, at the right time and the right place, is in fact the most efficient and the least expensive treatment. The trick is to break down the old silos of health care delivery in a way that is more adaptable and more effective for patients and their caregivers. Caregivers are part of this too, and it's important to support them.

LH: What are some of the changes you've seen within advance care planning and end-of-life care throughout your professional experience?

JG: We've had advance directives for 40 years, but with most advance directives, the health care system wasn't usually involved in helping people craft those things. An individual would go to their lawyer, or they would complete it on their own. Often they would not share it with the appropriate people, nor would they have the appropriate informing conversations to make their advance directive really effective and useful. Now, because of the changes in demographics, the changes in healthcare options available, and because more people are living longer, and with serious illnesses, a lot of those people arrive at situations where they lose decisional capacity. Their families and friends are then put into a decision making role that they are often not ready for. So we're seeing that advance directives are increasingly important to help address a lot of these situations. Since they are becoming more important, the healthcare system is now beginning to pay attention to them, and beginning to get involved in helping people make more useful advance directives.

This leads into what the Delaware Orders for Medical Treatment (DMOST) is all about; it is not strictly an advance directive, it's a tool that helps us have the communication and conversations with patients and families that we need to have in order to direct their care appropriately. When that form can be appropriately filled out, and with the right

conversations, it can direct the plan of care for that individual in a much more effective way. The best outcome for every patient, every time, that's what we're trying to achieve, and a well informed patient and family is certainly one way to accomplish that. DMOST is a tool that allows us to guide that conversation and then document the decisions that are made, so this conversation doesn't need to be had over and over again, and in every setting that person goes to, but remains nimble enough to be amended or adjusted as circumstances require.

LH: You've been involved at the forefront of the DMOST process. Have you been involved in any other changes, similar to DMOST, with advance care planning?

JG: I'm trying to get others to embrace advance care planning as a strategic initiative across the whole system, and I'm in the process of applying for a grant to do that. I haven't really done much community grassroots organizing related to advance care planning but maybe in the future.

LH: What do you hope to see in the future with advance care planning, or what changes, other than those previously mentioned, do you hope to see implemented?

JG: With the old type of advance care planning, only about 20-30% of the population had advance directive. There are little pockets around the country where with a concerted, organized effort, most of the population could have an advance directive. I'd like to see Delaware get to that point. I'd like to see us get DMOST up and running, and utilized appropriately across the state, as well as a statewide electronic registry for DMOST. There's a lot of work to be done in that area, and again, all providers should be aware of the importance of advance care planning and engaged in this at some level. Palliative Care, specifically, is a piece of this aimed at the population that is living their lives with serious illnesses, focused on supporting this population in a better way, whether it be at home, in a long term care facility, or in the hospital.

LH: Finally, what do you want readers to take away about end of life decisions and care from this issue of the DJPH?

JG: I'd like them to realize that end of life care is increasingly important and it's changing. I would encourage them to read the book "Being Mortal: Medicine and What Matters in the End"; and I'd like them to realize that by being informed, they can have the best chance to advocate for themselves and their families. It's important to have these conversations and be prepared, and it's about living as well as you can, for as long as you can. End-of-life decisions and care are not something to be so fearful of, and this shouldn't be a taboo subject. This shouldn't be a taboo subject. ■

John J. Goodill, MD, is the Director of Palliative Care Education and Outreach at Christiana Care Health System. Appointed in 2005, Dr. Goodill participates on an interdisciplinary team that provides consultations for hospital patients who are in the advanced stages of diseases such as cancer, renal failure, heart failure, and dementia. His team also works with patients who have chronic critical illnesses or failure of several organ systems. Additionally, Dr. Goodill is Co-Chair of Christiana Care's Ethics Committee. He concurrently works for the health system as a clinical instructor in medicine and is past director of the Adult Cystic Fibrosis Program.

Dr. Goodill has worked in private practice as a pulmonary medicine specialist since 1987, the same year he joined CCHS as an active staff member. He was a partner in Pulmonary Associates of CCHS. He is board-certified in internal medicine, pulmonary disease, and hospice and palliative medicine. He is a fellow in the American College of Chest Physicians and American College of Physicians and is also a clinical instructor at Jefferson Medical College of Thomas Jefferson University in Philadelphia.



John J. Goodill, MD, Chief,
Palliative Care Section CCHS



The Importance of Advance Health Planning

| by Nathan Kottkamp, Esq.

Ben Franklin wisely quipped: “Nothing in life is certain but death and taxes.” Unfortunately, without a specific deadline on the death issue, most of us put off the planning for it—as well as the health crises that often precede it. In fact, it is estimated that 75% of Americans have never taken the time to discuss their wishes or provided any written guidance to loved ones or healthcare providers in the event they are unable to speak for themselves. The consequence of such inaction is a very real public health issue in which care is often delayed, more expensive, and traumatic to loved ones.

Recognizing this, National Healthcare Decisions Day (“NHDD”)(www.nhdd.org), April 16, exists to encourage and empower all Americans to take the simple steps to be ready for the unexpected, to provide the gift of guidance to their loved ones, and, ultimately, to be sure that patients get the care they want and need if they are ever unable to speak for themselves. Professionals of all sorts can play a significant role in the effort to highlight the importance of making advance health care decisions and to provide tools for making these decisions. For health care providers, discussing advance care planning should be a routine component of patient encounters. For health care, family, trusts and estates, and elder lawyers, this is an issue of great importance to clients. Furthermore, financial planners should discuss the implications of complex medical interventions with their clients. For any professional seeking pro bono experience or an opportunity for public speaking, NHDD offers that, too.

In the debate about national health care reform, we witnessed a media firestorm over “death panels.” A decade ago, the Terri Schiavo case gripped the nation. And, nearly thirty years ago, the case of Nancy Cruzan (whose case, like Schiavo’s, involved a request to remove a feeding tube) went all the way to the U.S. Supreme Court. The Cruzan case also led to passage of the Patient Self-Determination Act and laws requiring nearly all healthcare facilities to inquire about advance directives. These cases have vividly demonstrated that many Americans have strong feelings about how we should treat those who cannot speak for themselves, how we want our own ends to be (if given a choice), and what makes life meaningful in the first place. Yet, only a small minority of all adults have executed an Advance Directive. A major contributing factor of this is that patients are often not asked in a meaningful way at hospitals or by healthcare providers in non-hospital settings. Indeed, one major study of patient records found that fewer than 50% of severely or terminally ill patients had an advance directive in their medical records—despite the fact that many of them had myriad interactions with the healthcare system before their major illness.

The reality is that advance directives (naming a healthcare agent and/or creating a “living will” regarding end-of-life wishes) are important regardless of age or current health. Simple proof: Cruzan and Schiavo were each in their twenties when their medical events struck. Beyond these high profile cases are those that come before ethics committees around the country every day because people do not have advance directives in place, even though there was plenty of time and a variety of good reasons to engage in advance care planning. Among others, these cases include:

- Patients who experience complications from elective surgical procedures;

- Unmarried pregnant women who experience post-partum complications;
- Residents of nursing homes who have acute health episodes; and
- Patients with a range of chronic and progressive conditions who have never been asked about their advance care wishes.

In many cases, the lack of advance care planning leads to a tragedy: families dealing not only with the grief of loved ones (of various ages) who are suddenly unable to communicate—and often near death—due to an accident or unexpected medical problem, but also the heartbreak of trying to figure out who should make healthcare decisions and what those decisions should be. In many cases, this uncertainty could have been prevented with the simple act of executing an advance directive. Even if an advance directive merely names an appropriate decision-maker, this choice goes a long way to improve situations in which patients cannot speak for themselves.

Ultimately, NHDD strives to provide much-needed information to the public, reduce the number of tragedies that occur when people’s wishes are unknown, and improve the ability of healthcare facilities and providers to offer informed and thoughtful guidance about advance healthcare planning to their patients. It also seeks to address the various misunderstandings in the public about advance directives, including that:

- People do not know the differences between a living will and a healthcare power of attorney.
- People believe advance directives are only used for limiting care.
- People assume that creating an advance directive is hard to do.
- People are unaware of the need to talk about healthcare planning when they are healthy (assuming severe illness or a catastrophic injury will never happen to them).

Significantly, there is no “agenda” for NHDD other than education and improving the ability to honor patients’ wishes. To that end, the event exists to encourage all people will discuss and document their wishes, whatever they are.

To be sure, all Americans should make their healthcare wishes known, not only to protect their own interests, but also as a gift to their loved ones. As mentioned above, professionals of all sorts should routinely encourage all their patients/clients to engage in thoughtful advance care planning. Consistent with all of this, a key theme of NHDD is to encourage professionals to “lead by example” and ensure that they have documented their own healthcare choices. Indeed, experience has shown that engaging in one’s own advance care planning makes it easier to discuss the topic with others.



Admittedly, advance directives have limitations, but the bigger problem is not with the documents themselves, but the failure to create them and honor them. Among the things that professionals can do is to:

- Lead by example—execute your own advance directive and see that your loved ones have done so as well
- Work with their individuals to ensure that they are in compliance with requirements of applicable laws on advance directives—state-approved forms are available in almost every state.
- Volunteer to speak at an NHDD event in the community (at a healthcare facility, library, religious institution, etc.)
- Give a continuing education presentation on advance directives (either public or in-house)
- Present an advance directives “brown bag lunch” session for your staff
- Write an Op-Ed on the importance of advance healthcare planning or present a PSA on the radio about NHDD
- Write a piece for your professional association’s magazine or on-line newsletter
- Offer free office hours on April 16 to provide the public with advance directives forms
- Volunteer to create or update your state-specific website on advance directives
- Visit www.nhdd.org for more ideas and resources
- Spread the word in the community and discuss the topic in places of worship, with civic groups, and with friends

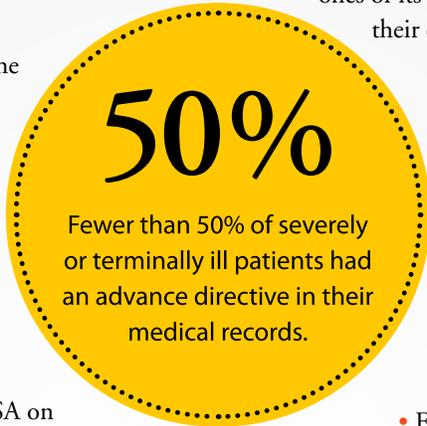
Many of the above are great opportunities for young professionals to gain speaking experience, retired professionals to stay engaged, and for all professionals to pick up some new clients.

NHDD’s motto is that “your decisions matter,” but a person’s choices may be of little or no practical use if they have not been communicated to others. In honor of NHDD, please take a few moments to reach out to relevant others (patients, clients, and loved ones) on April 16 (or the whole week or month) to encourage them to decide, discuss, and document their wishes, whatever they may be. For those people who already have an advance directive, encourage them to use April 16 to revisit the document to be sure it is still accurate and remind their loved ones of its contents—as well as the need for them to write their own.

For healthcare providers, there are numerous steps that can be taken to facilitate advance care planning:

- Re-examine any existing advance directives policies and/or create new ones.
- Ensure that staff are documenting, in a prominent part of the patient’s record, whether the patient has an advance directive.
- Ensure that professional and support staff are educated on the topic.
- Ensure that there is up-to-date information and forms available for patients that is consistent with applicable state law.

The website www.nhdd.org has a variety of free information, including free advance directives forms for every state, and tools to assist with thoughtful reflection on healthcare choices. Please use these resources and share them with others. ■



Nathan Kottkamp, Esq., a partner with McGuireWoods, LLP, in Richmond, VA, is the founder and chair of National Healthcare Decisions Day, a grassroots collaborative effort to inspire the public and providers to take action with respect to advance care planning. He can be reached at nkottkamp@mcguirewoods.com.



NATIONAL HEALTHCARE DECISIONS DAY

★ your decisions matter ★

National Health Care Decisions Day (NHDD), **April 16**, is a day set aside to inspire, educate and empower the public and healthcare providers about the importance of advance care planning. NHDD is an initiative to encourage people to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be. The NHDD theme this year is: “It always seems too early, until it’s too late.”

April 16 will be here before we know it, so be sure to take action now. There is no cost to join this important initiative. There are lots of free resources for engaging in conversations and for documenting wishes at www.nhdd.org. Click here for more information on how to help your patients and families become more proactive with their health care decisions.

Healthiest Nation 2030

Let's make America the healthiest nation in one generation.



APRIL 4-10

National Public Health Week 2016

#NPHW





The Increasing Importance of Advance Care Planning

“I have an Advance Directive not because I have a serious illness, but because I have a family” — Ira Byock, M.D.

Advance Directives (AD) have been around for 40 years. However, they have not been very effective in directing medical care for a number of reasons.

Historically, the health care system has not been involved in the creation of most Advance Directives. Typically, an individual would complete a form with their lawyer while they were creating an estate will. Otherwise, they would complete a form on their own, and this form would end up on a shelf somewhere. Key elements were often missing from this process including: the informed communication and conversation with loved ones, the appointed Power Of Attorney (POA), and the individual's health care provider. Furthermore, the language of an AD was often overly legalistic and difficult to apply to a particular medical situation. In most cases, the document was not where it needed to be to be effective. All too often an individual's family, and even the designated POA, would not know the AD existed, nor would they understand what the document entailed. In fact, only about 20-30% of the general public even had an AD; there was fear an AD would be used to withhold or limit beneficial treatment.

Something is Changing!

The need for clear, effective ADs is increasing for a number of reasons. First, there is an greater number of people living longer, but not necessarily better¹. Often quality of life decreases as time goes on due to a growing burden of chronic, progressive illness. We are now facing more options, and increasingly complex choices for medical care towards the end-of-life, which sometimes turn out to be false choices. By providing a false expectation of benefits from perceived choices, additional suffering, and even harm, occurs². As groups like the Baby Boomers age, there is more emphasis placed on patient to participate in decisions regarding their medical treatment. However, more individuals are unable to participate due to loss of decisional capacity, as severity and burden of illness progresses.

There are good examples of how robust engagement and programming within a health care system or community can lead to effective communication and conversation that, in turn, leads to a much greater percentage of the population having a useful and effective AD³. This improved communication and more effective ADs, have been shown to lead to medical care more closely aligned to personal preferences and values.

Most people do not want to die before they need to, and there is much uncertainty about when that might be for each individual. Dying in America has become an increasingly difficult and complicated affair^{1,6}.

Many of us fear the process of dying more than death itself. We all share a common humanity and mortality but we do not all have the same ideas about what makes our lives worth living, or what we might be willing to endure to continue living. For these reasons, in order to ensure we each get the medical treatment consistent with our own values, preferences, and goals, we must be prepared.

The process of Advance Care Planning (ACP) refers to the communication/conversation family and medical providers about the wishes, preferences, and goals one has for medical treatment, as well as the decisions and documentation that result from that communication in the form of an Advance Directive (AD) (Living Will, Durable Power Of Attorney (DPOA)) and also a Delaware Medical Orders for Scope of Treatment (DMOST) in the appropriate circumstances (*Appendix 1*).

It is recommended that every adult person consider making an AD to help guide care decisions during a time this person may not be able to participate in such decisions. The conversation, preferences, and decisions change with circumstances so that an AD may need to be revisited regularly.

As a person enters the final phase of their life, and they can see more clearly how their life might end and which medical treatments will be helpful and which may not, the DMOST medical order form (for Delaware residents) with its clarity and specificity, has been shown to be effective in aligning a person's medical care to their preferences⁴. A person or their surrogate decision maker (when the person no longer has decisional capacity) may complete this medical order form with their health care provider. This order can be modified or voided and should be consistent with previous AD. It is the most recent document that should be honored.

It should be emphasized that while an AD and DMOST are both voluntary legal documents, and there is a requirement to acknowledge and honor their direction, there is often room for interpretation and application to a particular situation. These documents should be viewed in the context of ongoing-shared decision-making and medical standard of care.

There are several resources that one could use to create an effective AD (*see appendix 2*). The steps outlined provide a general guide with an emphasis on communication and conversation with loved ones and health care providers.

Regulations for Delaware's new DMOST form have been finalized. Education for the public and training for providers on the DMOST form will be forthcoming in the next several months leading up to its availability as of April 1, 2016. This medical order form is designed for people generally in the last year of their life.

The public is demanding more accountability for their wishes. Providers are increasingly aware of the importance of ACP and goals of care conversations in driving an individual's plan of care. CMS has recently decided to reimburse providers who complete ACP with patients⁵. As the health care systems find new and

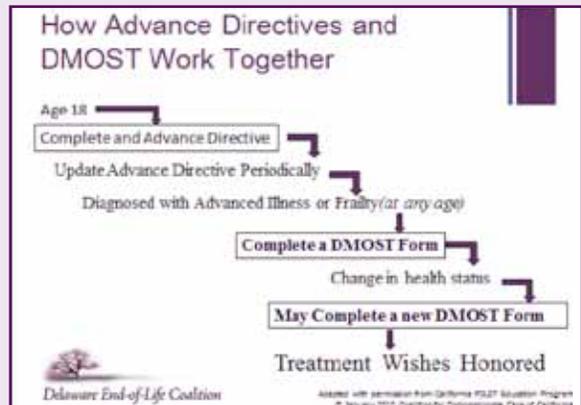
better ways to integrate AD/DMOST forms into the EMR and electronic registries like Delaware Health Information Network (DHIN), ACP will play a more important role in the provision of person-centered care for everyone. ■

John Goodill, M.D.

**Director, Palliative Care Education and Outreach
Christiana Care Health System**

- 1 Gawande, Atul. *Being Mortal: Medicine and What Matters in the End*. Metropolitan Books. Henry Holt and Company. 2014
- 2 Gorenstein, Don. *How Doctors Die: Showing others the way*. Nov 19, 2013 NYT
- 3 Pecanac, KE, MS RN, et al. Respecting Choices and Advance Directives in a diverse community. *J Pall Med* 17 (3) pg 282-287. 2014
- 4 Hickman, S et al. Use of POLST Program in clinical setting: A Systematic Review of the Literature. *JAGS* pg 341-350. Feb 2015.
- 5 CMS.gov. Proposed policy, payment, and Quality Provisions changes to Medicare physicians fee schedule for calendar year 2016.
- 6 IOM/NAM. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Sept 2014.

APPENDIX 1



Difference Between an Advance Directive and DMOST

	ADVANCE DIRECTIVE	DMOST
For whom	For all adults	For persons of any age with advanced illness whose healthcare provider would not be surprised if they died within the year
Purpose	To express values and appoint a surrogate (future wishes)	Medical orders which turn a patient's values into action (applies today)
Who can complete	Any adult with decisional capacity	Completed by individual authorized rep and health care provider
Guide treatment decisions in the hospital	Yes	Yes

Delaware End-of-Life Coalition

APPENDIX 2

Websites

- POLST.org
- Delawaremolst.org
- PREPAREforyourcare.org
- Mydirectives.com
- Getpalliativecare.org
- Palliativedoctors.org
- Theconversationproject.org
- CoalitionCCC.org

A Promise to Auntie Bini:

by Kathleen W.
McNicholas, M.D., J.D.

Lessons From a ‘Work Around’ and the Value of Delaware Medical Orders for Scope of Treatment (DMOST)

Auntie Bini was born on December 16, 1920 in Chicago. She was born at home and never hospitalized. She lived in the same home for most of her life and cared for her parents until their deaths. She worked as a hairdresser until she was in her 70's. Once retired, she downsized from her home in Bucktown, and moved to an apartment 2 miles north in Chicago. She lived alone and never married (she had a serious beau, however). In December of 2000, Auntie Bini celebrated her 80th birthday in Delaware with her nieces and nephews. She was surprised; this was the first birthday party she ever had, as Christmas always took priority around that time of year.



*Auntie Bini's (center)
90th birthday*

During frequent phone calls we were always told “not to worry” about her. We trusted her but were concerned about her determined independence, and shocked by some of her stories. She attended church regularly, even during the harsh Chicago winters. When driving was hazardous by her high standards, she chose to walk. Once, undeterred during a blizzard, she slipped and fell into a snow ditch. She was delighted, though somewhat embarrassed, when two large tow truck drivers helped her from the ditch, and she continued on to church.

Failure to reach her on several occasions resulted in calls to her nearby hospitals and police stations, we then arranged for “well person” checks on a regular basis. Not deterred by her age, she continued to drive, walk, shop, visit friends, and participate in her church. She even joined a mended hearts group, even though she had no history of heart disease.

September 11, 2001 marked the start of a new era for Auntie Bini and our family as worries about her safety were mounting; unable to reach her by phone that day, plans were made for a drive to Chicago to ensure Auntie Bini's well being. A niece who was not involved in this plan, was designated to be the driver.

Many conversations took place concerning Auntie Bini moving from her home in Chicago to Delaware. The Easter following her 80th birthday, she travelled east to celebrate what would be her eldest niece's last birthday. She returned again in late July for her beloved Mary's funeral. Moving Auntie Bini to the east coast was a frequent topic of conversation during that visit.

By the summer of 2004, she decided it was time to move permanently, but only on her terms. By firm agreement, she would maintain her high degree of independence. Her car soon arrived at her new home. The residence was modified to meet her needs and standards, and included a glass enclosed elevator (no small, dark places). She maintained her own set of rules-her dogs would be spoiled solely by her, her housekeeper would be Polish, and she would say who was and was not welcome to visit her, when, and for how long.

She adjusted well to her new residence, but still missed her home in Chicago. She kept in touch with her many friends and regularly received news of deaths which she accepted as a “fact of life”. She gifted her car to a great nephew who travelled from Chicago to drive it back there, much to her delight. In terms of her health, she loved Dr. Heldt, her new internist, as well as her new dentist, and ophthalmologist. She still enjoyed her frequent pedicures, too.

She had outpatient cataract surgery. Her first inpatient hospital experience was by ambulance, for an incarcerated umbilical hernia. An ambulance was resisted but needed. She stayed overnight at the hospital after surgery, and was determined that would be her last hospitalization.

After her return home from the hospital, she was determined her wishes for receiving further medical treatment would be honored. In her closet, an old suitcase contained her advanced directive, as well as her many insurance policies. She wanted assurance that these wishes would strictly be honored. She wanted no heroics and wished to die at home, in her own bed. There was agreement and a promise was made to honor all of her requests; however, there were some questions as to whether these promises could be kept.

She continued to do well and her only medication was a low dose thyroid supplement, as well as a mild antihypertensive prescription drug. Degenerative disc and joint disease were treated with increasing doses of Acetaminophen after an 'open MRI.' An outpatient arthroscopy then confirmed progressive joint deterioration. Injections gave her temporary relief, as she would not even consider joint replacement as an option. Walking continued to be a challenge. She started to walk with a cane and welcomed wheelchair assistance. She was quite upset with her increasing lack of mobility. However, she did continue to knit and work on her much treasured afghan blankets.

Throughout the year, she spent most of her time during the week in Delaware, and spent the weekends and summers at the Jersey Shore. She was always in the company of her beloved Bichons, Myocardium (known as My My or Mya) and Bradycardia (known as Brady). Auntie Bini wore a medic alert medallion at all times to reassure her and her family she was safe (she thought).

She had one brief episode of dizziness while getting off of her elevator. She was subsequently helped to the couch and thoroughly examined for signs of a neurologic event. When asked if this had ever occurred before she

others were present in the bedroom. While all thought the crisis had been averted, it soon became clear that the excitement was just beginning. The Emergency Medical Responders arrived and responded to the scene. Auntie Bini was alert, and was attempting to answer questions EMRs were directing to others. Despite her protests, EMRs insisted on placing an immobilizing collar on Auntie Bini's short, thick, neck, which had been deformed by arthritis, but was uninjured. She has significant kyphoscoliosis, and this extreme curvature of her spine made it difficult to place her on the backboard.

She pleaded with emergency responders to refrain from using the backboard, but was told the EMRs are in charge and have to protect their license. The police were next summoned to control the "unruly" family member that was trying to "interfere"

She wanted assurance that these wishes would *strictly* be honored. She wanted no heroics and wished to die at home, in her own bed.

responded "Yes, but I was told it was my blood sugar." The 911 call was then aborted and orange juice administered. Once again, there was a firm discussion about advanced directives, and Auntie Bini was reassured. She spread the word to her companions.

All was well until she slipped hurrying into the bathroom during a bout of gastroenteritis. No injuries were sustained, but efforts to reposition her failed. A reluctant call to 911 was made through her medical alert device. A booming voice projected from the base station located on the first floor. The landline was then taken over and we were told the call could only be handled by Emergency Medical Responders (EMRs). A neighbor responded and soon several

with their care. Amidst Auntie Bini crying, her niece protesting, and the neighbors standing by in amazement, EMRs proceeded to place her small, though stout, frame on an ill adapted backboard. To add to the discomfort, she was taken down the stairway instead of the elevator which would have safely accommodated her. Throughout the trip down the stairs, EMRs struggled while loudly yelling "slipping, slipping!" That trip to the hospital, confirmed gastroenteritis and no evidence of trauma. This was her final entry into a medical facility. Again, Auntie Bini's promises were reaffirmed. The summer of her 89th year went well, spent at her Jersey Shore home, and with the changing seasons, she returned to her home in Delaware.



In the fall, a syncopal episode resulted in her caregiver calling her physician, her dog walker contacting her niece, and her Polish housekeeper comforting her. Knowing full well Auntie Bini's wishes, the dreaded medical alert medallion would not be touched, and no one dared to call 911. A long discussion later that afternoon in her physician's office reaffirmed her goals and wishes of remaining in her home. Hospice was next consulted. In addition to enjoying the company of her caregiver, housekeeper, dog walker, neighbors, family, and church members, she now had additional company of hospice staff, including a care planner, social worker, a chaplain, and nurses. She remained busy and secure with exceptional care.

She prepared for her not-so-surprise 90th birthday party by making gifts for all who attended. She celebrated a wonderful life and looked forward to a natural death. She was able to see her family grow, as her great-great nephew turned 2 ½ years old, and 2 new babies were born that April. She joined them at the Jersey Shore in early June. Although her pain worsened, and her mobility decreased, she was able to enjoy time with the new mothers, Abby and Paige, and her great-great nephew Jack, and her two dogs, as her constant companions. The transition of the hospice teams and care teams from Delaware to the Jersey shore was seamless. She loved her caregivers and nursing team.

She had positive interactions with them, entertaining them with tall tales until a sudden deterioration occurred. She was cared for in her own bed, in her own home by a professional team as well as her family and friends, including Dr. Curtin and the nuns from Villa Maria by the Sea. She died peacefully after watching a Phillies victory. She always wanted to celebrate with others; so her funeral entailed a Mass and luncheon at the Jersey Shore, followed by another Mass and luncheon in Delaware, all prepared by her favorite caterers, who were also friends.

The promise for Auntie Bini to die naturally in her bed was honored through a "work around." Today, with DMOST, (The Delaware Medical Orders for Scope of Treatment Act) promises, such as Auntie Bini's, can be assured through legislation. The Emergency Medical Responders would also be able to support her decisions and requests through provisions of the statute. Physicians and patients are now able to work together regarding decisions in end-of-life planning, even in cases without a terminal illness but frailty, when death is anticipated. Individuals in similar conditions to those experienced by Auntie Bini, as well as their family members, can be confident in their decisions, and the commitment to their promises can be fulfilled. ■



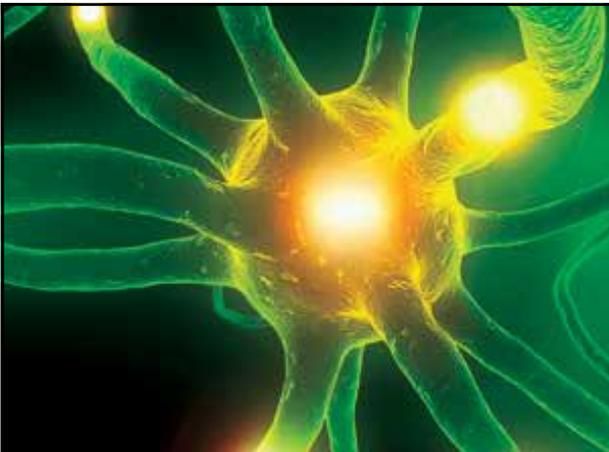
Lori's Hands

Community Health Service Learning

Lori's Hands 2nd Annual Picnic Event
Hilton Christiana • Saturday April 2, 2016

Event details and registration will be available online at:

www.lorishands.org



4th Annual Neurovascular Symposium

Continuing Physician
Professional Development/CME



Guest Speakers

Lori Billinghamst, M.D.,
MSc, FRCP

Hana Choe, M.D.

Lawrence Tanenbaum, M.D., FACR

Local Speakers

Leif-Erik Bohman, M.D.

Mary Ciechanowski,
MSN, APRN, ACNS-BC

Todd Harad, M.D.

Ralph Ierardi, M.D.

Kendra Koehler, Psy.D.

Jenna Logan,
MSN, APRN, ACNP-BC

Michael McCulloch, M.D.

Susanne Morton, PT, Ph.D.

Jonathan Raser-Schramm,
M.D., Ph.D.

Sudhakar R. Satti, M.D.

Thinesh Sivapatham, M.D.

Waimei Amy Tai, M.D.

The Neurovascular Symposium will focus upon the diagnosis, rapid triage, and treatment options for acute stroke at a comprehensive stroke center.

Friday, April 8, 2016

8 a.m. – 3:30 p.m.

**(Registration and exhibits
begin at 7 a.m.)**

John H. Ammon Medical Education Center
Christiana Hospital Campus
Newark, Delaware

Fee: Christiana Care registration (Medical-Dental Staff employees) – \$55 in advance (\$75 “day of” registration, if seating permits)
Non-Christiana Care registration – \$75 in advance (\$95 “day of” registration, if seating permits)
Full-time students – \$20

There is no charge for Christiana Care residents and fellows to attend. (Registration is required.)

Christiana Care Continuing Medical Education will not refund registration fees in the event of cancellations.

Registration Deadline: March 25, 2016.

Pre-registration required. Register online:
<https://cchs.cloud-cme.com/Neurovascular2016>

Questions: Email Robin Pugh at rpugh@christianacare.org.

Dr. Timothy Langan, MD
Medical Director, VITAS Healthcare

Keagen Brown, MBA, CPHIMS
General Manager, VITAS Healthcare
President, Delaware End-of-Life Coalition

Impact of DMOST on Hospice and End-of-Life Care

The publication of the DMOST (Delaware Medical Orders for Sustaining Treatment) regulations on January 1, 2016 is a significant step forward for end-of-life care in the First State. Routinely in hospice care families find themselves making decisions for loved ones who have not communicated their desires for care at the end-of-life. Several initiatives are culminating that will facilitate the conversations around these decisions more common-place and DMOST is the first step in making the conversations a reality.

The DMOST form covers all major decisions that a patient facing a life limiting illness should be communicating their choices. These areas are:

- Their overall goals of care
- CPR / DNR
- Intubation
- Medical Interventions (Full Treatment, Limited Treatment or Comfort Measures)
- Artificial Nutrition / Hydration
- Hospitalization

DMOST is meant to cover end-of-life decisions across the spectrum of health care, from the home, to the EMS provider, to the doctor's office, to the hospital and through to the long term care facility. No longer will each part of the medical system need to have patient's fill out their own forms.

Provision of Payment for Physician Conversations on End-of-Life

Beginning in 2016, Medicare will begin reimbursing physicians and advance practice clinicians for having conversations with patients around their end-of-life goals of care. This additional payment will utilize CPT code 99497 and pay roughly \$86 for discussions of advance directives with the patient, a family member, or surrogate for up to 30 minutes. An additional 30 minutes of discussion will use code 99498 and pay \$75.

The goal of this new opportunity is to ensure that "patients [can] discuss whether and how they would want to be kept alive if they became too sick to speak for themselves. Doctors can advise patients on options for end-of-life care, which may include advance directives to forgo aggressive life-sustaining treatment."¹

This conversation is the crux of the goal around DMOST. During the May 21st DMOST seminar held by the Delaware End-of-Life Coalition, Dr. John Goodill, M.D., FACP, FCCP said, "It's not about filling out a form, it's not about having another physician order, it's about a conversation. A meaningful conversation where a physician or mid-level practitioner is empowered to have a meaningful conversation with a patient and for that patient to make an informed decision."

That's what DMOST is in a nutshell. It is meant to make the transitions of patients who are facing life-limiting illnesses easier and to ensure their wishes are respected along the way. DMOST is meant to encourage conversation so that patients can fully express their end-of-life goals while they are still able. This new reimbursement will ideally financially compensate providers for time taken to have these complex conversations with patients and families before they are facing a critical illness.

Impact of DMOST on Patients and Families Receiving Hospice Care

Currently when a transition of care occurs anywhere in medicine, each patient runs the risk of their choices not being honored. This lack of respecting the patient's autonomy is not due to negligence; however more likely due to lack of knowledge of providers of the choices made, or lack of agreement between the patient and medical decision maker in times of stress.

It is not rare that patients present with a hospice appropriate illness but yet have not fully had a detailed discussion with their health care provider in regards to their end-of-life decisions. Thus, it is often left to the hospice interdisciplinary team of physicians, nurses, social workers and chaplains to help the patient and families ascertain their wishes. Additionally, hospice providers, while providing care, have on-going conversations with patients and families surrounding the desires for end-of-life care as there are often second thoughts or changes in what patients and families want or desire. The choices are documented in the clinical chart and the patient and families are educated on the impact of the decisions. When these choices are discussed in the moments of calm towards the beginning of care, it is routine that both the patient and family will be in agreement. However, when a symptom exacerbates, and the decision to provide more highly acute care versus allowing the disease to follow its normal course arises there can be a disconnect between the original discussion and the course of treatment followed.

In these times of stress, some families, acting as surrogate decision makers, will make an independent decision to transport the patient to the emergency department of the hospital and, through no ill-intent, neglect to inform the ED staff of the patient's hospice election.

They will make comments such as "Do everything possible," or worse, put the burden of the decision on the medical professionals and fail to communicate with those professionals the decisions previously made. In M.M. Shultz's 1985 article she shares, "Decision making by competent professionals does not provide adequate substitute for patient choice. Injuries that arise from invasion of patients' interest in medical choices are both substantial and distinct."² Often due to fear by surrogate decision makers, end-of-life choices are overridden despite the patient's original goals.

If implemented effectively within each hospice organization, DMOST will significantly change this experience for patients and families. If DMOST is completed before the patient has an acute change in condition, it allows their wishes to be better recognized and respected across the continuum of health care.

Goal of the DMOST form and the Hospice Face-to-Face Encounter

The hospice face-to-face encounter is a Medicare requirement for patients entering their third benefit period. Medicare covers hospice services for individuals who elect to receive hospice care instead of aggressive treatment of a terminal illness. Upon admission, a patient's physician and the hospice medical director must certify that the patient's life expectancy is six months or less if the illness runs its normal course. This starts the benefit period cycle where patients are eligible for two 90-day hospice benefit periods followed by an unlimited number of 60-day benefit periods.

The Medicare Hospice Conditions of Participation state that "As part of the certification requirements for a hospice patient's 3rd or later benefit period, a hospice physician or hospice nurse practitioner must have a face-to-face encounter with the patient to gather clinical findings to support continuing eligibility for hospice care." This

encounter creates the perfect environment for a physician to have the conversation around end-of-life choices.

The hospice face-to-face visit by the physician or advanced practice clinician now can be a catalyst to ensuring each patient understands the value of the DMOST form and if they so choose, completes one within the scope of that visit.³

While the ideal is for conversations around goals of care to be held prior to the patient nearing the end-of-life, the reality is that the majority of patients are not prepared to have these significant conversations while still hospitalized. When the patient is home and comfortable they often will be more prepared to have the conversations. The hospice Face-to-Face Encounter is another opportunity to have that discussion in an environment where the patient may feel more autonomy to make decisions.

Naturally, those hospice patients who have not made a decision as far as DMOST is concerned and whose illness may be shorter than 180 days may need a hospice physician or nurse practitioner visit earlier in the course of the illness. This often can be accomplished under the routine care given under the Medicare Hospice Benefit.

These are the decisions that are made in times of calm but are routinely forgotten in times of stress. The implementation of DMOST within hospice care will significantly improve the follow through of patient wishes and goals of care. ■

Bibliography

- ¹ Pear, R. (2015, October 30). New Medicare Rule Authorizes 'End-of-Life' Consultations. *New York Times*, p. A14.
- ² Shultz, M. M. (1985, December). From Informed Consent to Patient Choice: A New Protected Interest. *The Yale Law Journal*, 95, 219.
- ³ The Delaware End-of-Life Coalition. (2015, 5 24). Understanding DMOST. Selbyville, DE, USA.

Health officials agree: no alcohol during pregnancy

To prevent birth effects and neurodevelopmental disabilities, pregnant women should not have a drop of alcohol, the American Academy of Pediatrics (AAP) recently declared.



Drinking during pregnancy greatly increases the chances that the baby will develop a fetal alcohol spectrum disorder (FASD). Prenatal alcohol exposure causes structural or

functional effects on the brain, heart, bones and spine, kidneys, vision and hearing. It's also associated with a higher incidence of attention-deficit/hyperactivity disorder, learning and behavioral problems, and emotional and social issues.

"We wholeheartedly support the AAP's announcement regarding no alcohol use during pregnancy," said Dr. Karyl Rattay, director of the Division of Public Health (DPH). "The only sure way to prevent FASDs is to completely avoid alcohol use while pregnant. This also applies to women who are trying to conceive. Damage from prenatal alcohol exposure can occur even during the earliest weeks of pregnancy, even before a woman realizes she's pregnant."

For tips for a healthy pregnancy and healthy baby, visit <http://dethrives.com/healthy-mothers>. Men and women struggling with addiction can visit <http://www.helpisherede.com/> for local resources, or call 800-652-2929 (New Castle County) or 800-345-6785 (Kent and Sussex counties).



Be prepared for winter power outages! Add your electric company as a cell phone contact, and post the number at home. Check your circuit breaker before reporting a power loss. Keep flashlights and battery-operated lanterns and radios handy.



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health
Office of Health and Risk Communications

Be familiar with Code Purple sites

During extreme cold events, Code Purple sites open in houses of worship and community centers. Homeless individuals and families can come out of the cold to sleep and eat hot meals. Many Code Purple sites often need volunteers and donations of money, sleeping supplies, and food. Other items include:

- blankets, cots, and sleeping bags
- towels, wash cloths, hand wipes, sanitizers
- feminine products
- hats, scarves, gloves, hand or feet warmers
- coats, boots, long underwear
- bottled water and instant hot drinks
- frozen meals and ready-to-eat food with easy-opening lids
- garbage bags and disinfectant spray

To connect with Code Purple resources, call Delaware 2-1-1 or use the Delaware 2-1-1 mobile app, or visit www.delaware211.org.

Use "31 Days to a Healthier You" tips

Start healthier habits with the help of DPH's "31 Days to a Healthier You" social media campaign. Use the hashtag #31DaysDE to view how-to videos, tips, and photos, such as:

- Follow the 5-2-1 Almost None concept: eat at least five servings of fruit or vegetables a day, get no more than two hours of recreational screen time daily, get one hour of physical activity each day, and drink almost no sugar-sweetened drinks. Less than 10 percent of calories should come from added sugars and saturated fats, according to the new 2015-2020 Dietary Guidelines for Americans, at health.gov/dietaryguidelines/2015/guidelines/.
- Under the Affordable Care Act, Delawareans have access to free health screenings; visit www.choosehealthde.com.
- Delaware residents 18 and older can quit smoking with free help. Contact the Delaware Quitline toll-free at 866-409-1858 or at www.dhss.delaware.gov/dhss/dph/dpc/quitline.html.

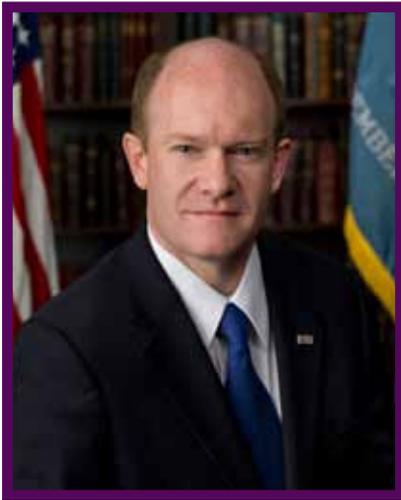


2016 Excellence Awards

May 5, 2016 - 6:00pm

Recognizing Excellence in

End-of-Life Care in the First State



Keynote Speaker:
Senator Chris Coons

To nominate someone who has provided excellent end-of-life care, please go to:

www.deolc.org/nominate

For more information, please contact us at:

contacts@deolc.org

Delaware End-of-Life Coalition

Educators, clergy, health professionals, caregivers, and community partners coming together





Delaware Medical Orders for Scope of Treatment Act

Keeping Control of Treatment Decisions | *by Wade Scott, Esq.*



Wade Scott, Esq.
The Delaware Elder
Law Center

And finally Ben has come to the end of his battle with cancer. Nine months have passed since he was diagnosed with a fast growing form of sinus cancer. The oncologist just finished explaining to Ben and his family that there is nothing more he can do and death is certain in the very near future. But the problem is that Ben is suffering terrible facial pain and has exhausted all forms of pain medication. The only remedy now is to undergo surgery to sever key facial nerves to give him relief.

Fifteen years prior to his diagnosis, Ben had executed his estate plan. The plan included an Advanced Healthcare Directive (Advance

Directive) and HIPAA release. In his directive, Ben had put in writing that he did not want to receive life sustaining measures should he develop an incurable disease or become permanently unconscious. Delaware law permits a person to determine in advance whether he wants life sustaining measures taken or not if he develops a qualifying condition: permanently unconscious or an incurable disease where death is certain.¹ The oncologist had included a Do Not Resuscitate (DNR statement) as part of the medical order guiding his treatment at Ben's request. When one enters a medical facility, all treatment is authorized by a standing medical order for treatment. In Delaware a medical order expires as soon as the patient leaves the premises physically. It is not transportable across different treatment venues.

Ben's doctor recommended a neurosurgeon in Philadelphia, PA to perform the surgery to relieve Ben's pain so he could die with dignity and peace. Ben was taken to Philadelphia by ambulance. On the way, he went into cardiac arrest. The ambulance crew resuscitated Ben successfully. He underwent the surgery and died in a hospice facility six weeks later. When the family was advised that Ben was resuscitated, they were shocked. How could this happen? Everyone knew that there was a DNR in place.

His advanced directive stated that he did not want to be resuscitated if he developed the very medical condition that he had.

What a sad scenario this is. Unfortunately, it is repeated over and over again. The problem is that most physicians view an advanced directive as advisory only and not mandatory.

Only a medical order dictating treatment is mandatory. An advanced directive is not a medical order for treatment. It is a legal document prepared by lawyers as part of the client's estate plan. It is executed well in advance of the client actually developing a qualifying condition. On top of this is that a medical order for treatment expires when the patient leaves the issuing facility. The result of all of this is that there are times when a patient's wishes concerning life sustaining treatment are not carried out.

At least this was the situation in Delaware until recently. The Delaware Legislature enacted the Delaware Medical Orders for Scope of Treatment Act ("DMOST Act") in May 2015, to address the patient's lack of ability to determine the course of treatment in the above circumstances.² The DMOST form is critical to making one's current wishes known in the context of failing health.

The DMOST form works in tandem with a patient's Advanced Directive. In an Advance Directive, the patient names a medical agent who will make treatment decisions if the patient cannot. It is executed before the patient develops a qualifying condition. The Directive expresses the patient's wishes at the time of execution. As the patient ages, his wishes may very well change regarding end-of-life treatments.

The DMOST form is there to address the then existing medical condition of a patient

DMOST means a clinical process to facilitate communication between healthcare professionals and patients living with serious illness or frailty whose healthcare practitioner would not be surprised if they died within the next year or, if the patient lacks decision making capacity, the patient's authorized representative. §2503 A. (c). The process encourages shared, informed medical decision-making. The result is a DMOST form, which contains portable medical orders that respect the patient's goals for care in regard to the use of CPR and other medical interventions. It is applicable across healthcare settings, is reviewable, and revocable.

16 Del. Code §2501A Definitions (c)

with significant health issues. This group of patients is relatively small in relation to the overall senior population. They are sick and have to make treatment decisions effecting the quality and duration of life. So, it is at this point in a person's life that the DMOST form becomes more relevant than the advanced directive concerning life sustaining treatment. The Directive, however, is still critically important in that it names a surrogate to make medical decisions if the patient cannot.

The statutory requirements for a valid and enforceable DMOST form are that it is a statement in writing, signed by the patient in the presence of a healthcare practitioner, setting out the patient's healthcare preferences. It must state that the form was signed after consultation with his healthcare practitioner. The healthcare practitioner must sign the form as well. Furthermore, it must state that the purpose and consequences of signing the form,

along with the fact that the form can be amended or terminated at any time, was explained to the patient by the healthcare practitioner.

The form must address the situation of a patient losing decision making capacity. The form has to provide the patient the option of specifically authorizing his designated agent to modify or void the medical order for treatment. If the agent is not authorized to do so on the form, he may not take such action. Therefore, it is best to directly involve one's medical agent

in this clinical process so that person is clear about the patient's wishes concerning treatment options.

The statute provides a mechanism to deal with conflicts concerning a patient's directives (DMOST form or Advanced Healthcare Directive). The last known directive of the patient controls. Where there is a conflict between the form and the patient's

advanced directive, the patient's last known verbal or written directive must be followed. The DMOST form, where earlier in time, shall be modified accordingly. Any modifications must take place only after consulting with a healthcare practitioner.

The statute provides that a properly executed DMOST form is to be honored across the full range of treatment settings, including the home and emergency situations. A healthcare practitioner is subject disciplinary action for not following the treatment directives in the form.

As a result of this new statute, Delaware citizens have a new way to control their wishes concerning medical treatment as they age. This is significant in light of the fact that Delaware has the 5th fastest aging population in the nation. ■

² 16 Del. Code §2501A. The DMOST regulations and DMOST form will be finalized in the fall of 2015 and become effective by May 2016.

The Evolution of Hospice Care: Expanding Access with the Concurrent Care for Children Provision

By Billie Winegard, MD, MPH and Wendy Sturtz, MD

Their son had metastatic cancer. His life expectancy was less than 6 months, and he was suffering with worsening pain and shortness of breath due to his disease. As his condition progressed, he needed frequent medical assessments for adjustments of the medications used to manage his symptoms, but the trips to the clinic were difficult for him and his family to manage as they lived some distance away from the hospital. Admission to the hospital also went against their goal of keeping their family together at home. However, when presented with the option of hospice to minimize his suffering and help him to maintain as high a quality of life as possible with close monitoring and care, the family was unwilling to give up the option of seeking treatments that might provide a cure.

The development of hospice care in the United States is relatively young and still evolving. Dame Cicely Saunders, who created the first modern hospice in a London suburb, first brought the idea of specialized care for the dying to the U.S. in 1963 (National Hospice and Palliative Care Organization, 2015). Almost a decade later, the first U.S. hospice was founded in 1974, and in the late 1970s, a task force of the U.S. Department of Health, Education, and Welfare determined that the hospice movement should receive federal support as it provided “more humane care for Americans dying of terminal illness while possibly reducing costs” (National Hospice and Palliative Care Organization, 2015). Since the creation of the Medicare hospice benefit in 1982, coverage for hospice care has expanded and is now provided under Medicare, Medicaid, and most private insurance plans and managed care organizations (“NHPCO’s facts and figures: Hospice care in America”, 2015).

The hospice model allows for a holistic approach model of care provided by an interdisciplinary team (“NHPCO’s facts and figures: Hospice care in America”, 2015). This team includes, at a minimum, a hospice nurse, social worker, chaplain, physician, and volunteers. The team members make regular visits and are available 24 hours a day, seven days a week to: manage the patient’s pain and symptoms; assist with the emotional, psychosocial, and spiritual aspects of dying; provide medications and medical supplies and equipment; and provide bereavement care and counseling to surviving family. Palliative care also has the goal of maximizing quality of life for patients with serious illnesses (Center to Advance Palliative Care). It is provided by an interdisciplinary medical team at any stage of illness to provide an extra layer of support.



“We’re not ready to give up. We *can’t* give up if there’s a chance.”

For children with life-limiting or life-threatening conditions, palliative care can be initiated at the time of diagnosis to provide symptom management, address psychosocial and spiritual needs, and assist with goals of care (Keim-Malpass et al., 2013). However, eligibility for hospice services, and the expansion of services that it offers, historically has had two requirements whether the patient is an adult or a child. The first was that the patient had a life expectancy of no more than six months; the second was that all life-prolonging, curative, or disease-directed care be discontinued (Lindley, 2011). Families in such hard situations were faced with the very difficult decision of whether to discontinue therapies such as chemotherapy, radiation therapy, dialysis, and medications such as

antiretroviral and transplant rejection therapies. Private duty nursing services, necessary for the safe care of many medically complex and technology-dependent children, would also have to be discontinued with the transition to hospice care (Bettini, 2013; Miller & Feudtner, 2013; Miller et al., 2012).

Forcing parents to make these nearly impossible decisions was alleviated with the passage of the Patient Protection and Affordable Care Act (ACA) of 2010 (Govtrack, 2009; Lindley et al., 2014). Included within Section 2302 of this large piece of legislation is the Concurrent Care of Children Requirement (CCCR). This provision was written in response to the growing voice of those who provide end-of-life care asserting that hospice eligibility requirements were preventing many patients, in particular

children, from receiving adequate care at the end of their lives. It makes an allowance for terminally ill patients under the age of 21 who are enrolled in Medicaid or Children’s Health Insurance Programs (CHIP) to receive both curative and hospice care thereby expanding access to the benefits of hospice care for children (Lindley, 2011). This legislation more aligns with basic principles of palliative medicine which recognize an individual person’s goals may include both pursuing life-prolonging disease-directed treatments while at the same time focusing on the best quality of life with thoughtful attention to emotional, social and spiritual aspects of care.

Enactment of the CCCR has occurred gradually. Almost 3 years after its passage, only 31 states had put the legislation into action with Delaware beginning implementation in 2011 (Lindley et al., 2014). While no economic, political, or legal factors have been shown to affect states’ implementation, several clinical challenges have been identified (Lindley et al., 2014; Miller et al., 2012). These challenges include: knowledge

of end-of-life care for this population; practitioner concerns about adopting a palliative care model of care with focus on comfort; coordination of care between hospice providers and other caregivers; reimbursement for services and durable medical equipment that could not be provided under the hospice per diem reimbursement model; and insurance coverage.

There is a pervasive belief in our society that children should not die. Because of this and common misconceptions, pediatric hospice referrals in particular have been viewed negatively – that there has been a failure or that the family or medical team has given up hope (Neeley, 2009). The goal of palliative and hospice care is not to take away hope but to provide care to ensure a good life no matter how long that life may be. With the passage of the CCCCR, an important step toward removing barriers to pediatric referrals for expert care to relieve psychosocial, spiritual as well as physical suffering has been taken. ■

Billie Winegard, MD, MPH is the current fellow in Pediatric Palliative Care at Nemours/ AI DuPont Hospital for Children.

Wendy Sturtz, MD is a physician at Christiana Care specializing in neonatology and pediatrics.

References

- Bettini, L. (2013). Concurrent care for children: How this new legislation has opened hospice care to children with high technology home care needs. *Home Healthc Nurse*, 31(2), 114-115.
- Center to Advance Palliative Care. About palliative care. Retrieved Jan 2, 2016, from <https://www.capc.org/about/palliative-care/>
- Govtrack. (2009). H.R. 3590 (111th): Patient protection and affordable care act. Retrieved Dec 26, 2015, from <https://www.govtrack.us/congress/bills/111/hr3590>
- Keim-Malpass, J., Hart, T. G., & Miller, J. R. (2013). Coverage of palliative and hospice care for pediatric patients with a life-limiting illness: A policy brief. *J Pediatr Health Care*, 27(6), 511-516.
- Lindley, L. C. (2011). Health care reform and concurrent curative care for terminally ill children: A policy analysis. *J Hosp Palliat Nurs*, 13(2), 81-88.
- Lindley, L. C., Edwards, S., & Bruce, D. J. (2014). Factors influencing the implementation of health care reform: An examination of the concurrent care for children provision. *Am J Hosp Palliat Care*, 31(5), 527-533.
- Miller, E. G., & Feudtner, C. (2013). Health reform law allows children in hospice to be treated for their disease. *AAP News*, 34(8), 1-2.
- Miller, E. G., Laragione, G., Kang, T. I., & Feudtner, C. (2012). Concurrent care for the medically complex child: Lessons of implementation. *J Palliat Med*, 15(11), 1281-1283.
- National Hospice and Palliative Care Organization. (2015, Jul 23). History of hospice care. Retrieved Dec 27, 2015, from <http://www.nhpco.org/history-hospice-care>
- Neeley, S. M. (2009). Barriers to pediatric hospice care. *Journal of Hospice & Palliative Nursing*, 11(1), 8-9.
- NHPCO's facts and figures: Hospice care in America. (2015, September). Retrieved Dec 27, 2015, from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf

“”

A QUOTE FROM SENATOR COONS



Sen. Chris Coons

“When I first ran for the Senate in 2010, I sat down with a group of Delaware physicians to get their thoughts on America’s health care system. They all told me the most important health care problem that they wanted elected leaders to fix was the lack of clarity around patients’ preferences for care in the event of serious illness or injury. Every doctor could think back to a case in which a patient faced a terminal illness and did not have long to live – yet each performed operations or interventions that the doctor didn’t think the patient would have wanted and that often came at an enormous emotional cost for the patient’s family.

“These conversations, in addition to countless others I’ve had with Delawareans up and down the state, showed me that we must do more to encourage patients and doctors to have these difficult, but critically important conversations. That’s why I introduced the bipartisan Medicare Choices Empowerment and Protection Act to help encourage these conversations by establishing a financial incentive for Medicare beneficiaries to create electronic advance directives, legal documents that allow patients to clarify their end-of-life preferences. I believe this bill is complementary to what’s already happening in Delaware through the implementation of the Delaware Medical Orders for Scope of Treatment, or DMOST. I commend the state legislature for taking this important step and look forward to partnering with state and local leaders to transform how we approach end-of-life care issues.

“None of us should have to spend the final months of our lives worrying about looming health care bills or complicated procedures, or navigating a complex maze of legal and medical decisions. We should be able to spend this time on our own terms: in comfort, in dignity, in the company of family and faith. The Medicare Choices Empowerment and Protection Act is a key step in that direction, and I will continue building on the strong support this bill has from both parties and a broad coalition of palliative care experts and religious organizations to see it over the finish line.”

FOR IMMEDIATE RELEASE: Wednesday, November 18, 2015

Bipartisan legislation is first of its kind to receive support from the National Right to Life Committee

WASHINGTON – U.S. Senators Chris Coons (D-Del.) and Bill Cassidy, M.D. (R-La.) and U.S. Representatives Diane Black (R-Tenn.), Mike Thompson (D-Calif.), Chris Collins (R-N.Y.), and Peter Welch (D-Vt.) today introduced legislation to encourage Medicare beneficiaries to create electronic advance directives, legal documents that allow patients to clearly articulate their preferences for their medical care should they suffer from a debilitating illness or condition. The Medicare Choices Empowerment and Protection Act would offer a small, one-time financial incentive to encourage Medicare beneficiaries to provide clear legal guidance to their medical providers and family members should they become incapable of speaking for themselves. With recent attention on the announcement from the Centers for Medicare and Medicaid Services to pay physicians for advance care planning, this legislation would incentivize Medicare beneficiaries themselves to create and register a certified and secure advance directive online. In addition, the bill would provide beneficiaries with access to a website with model advance directives representing a range of options.

Orienting DMOST within the advocacy, provider, and regulatory framework of Delaware entities

The following institutions and their contact information is a foundational listing of the many groups who have been, or will be, engaged in the State of Delaware DMOST initiative run under the Delaware Academy of Medicine's "Goal of Care Delaware" program. We have made every attempt to be inclusive, however, this is not an exhaustive list. In addition, the DMOST implementation and training program will ramp up in 2016, and inclusion in the list below in **no way** implies that all of these entities are experts in DMOST at this current time.

State of Delaware

delaware.gov/

Department of Health and Social Services

dhss.delaware.gov/dhss/

(302) 255-9668

DHSS's mission is to improve quality of life for Delawareans by promoting health and well-being, fostering self sufficiency, and protecting vulnerable populations

Division of Public Health

dhss.delaware.gov/dhss/dph/index.html

(302) 744-4700

DPH includes a range of programs and services, and is focused on improving the health of those who live and work in Delaware

Office of Emergency Medical Services

by state service center

dhss.delaware.gov/dhss/dssc/emerast.html

Assists with funds for rent, utilities, and emergency shelter for eligible persons to help maintain self-sufficiency and prevent homelessness

Division of Long Term Care Residents Protection

www.dhss.delaware.gov/dltcrp/

302-577-1406

Protecting residents in Delaware long term care facilities through promotion of quality of care, quality of life, safety, security, and enforcement of compliance with State and Federal regulations

Long Term Care Ombudsman

www.dhss.delaware.gov/dhss/dsaapd/lcop.html

1-800-223-9074

Advocates for residents who live in long term care facilities, as well as those in other settings, and receive home and community based services

Delaware End of Life Coalition

Strengthening collaboration between the public and professional communities of Delaware regarding end of life issues, and to stimulating public and professional awareness, share knowledge, and create change so every Delawarean is aware of issues and choices related to the end of life

Delaware Hospice

www.delawarehospice.org/

800-838-9800

Community-based, not-for-profit hospice organization in Delaware, committed to providing the highest quality of hospice care to the community it serves

Compassionate Care Hospice

cchnet.net/mid-atlantic/delaware/

302-421-4690 (Wilmington)

Providing home health, hospice, and palliative care in multiple US states

Heartland Hospice

www.heartlandhospice.com/find-an-agency/heartland-hospice-services-of-heartland-hospice-house-of-de/

302-239-2961

Providing hospice services, focused on personal and memorable experiences

Vitas

www.vitas.com/de/delaware-hospice

302-451-4000

Providing customized hospice care for patients near the end of life, focusing on patient care facilities, as well as patients' homes

Seasons Hospice

www.seasons.org/

866-433-9856

Community-based organization providing hospice care and finding creative solutions to add quality to life

Christiana Care Visiting Nurses Association

www.christianacare.org/vna

1-888-862-0001

Providing at home medical help and alternatives to extended hospital stays or nursing home stays after an illness, injury, hospitalization, or longer-term care

Delaware Healthcare Association

www.deha.org/

302-674-2853

Association formed to assist Delaware Hospitals in working on issues concerning health care and the hospital industry

Alfred I. duPont Hospital for Children

www.nemours.org

302-651-4000

Pediatric Hospital located in Wilmington, DE

Bayhealth Medical Center

www.bayhealth.org/

302-674-4700

Healthcare System serving the central and southern parts of Delaware

Beebe Healthcare

www.beebehealthcare.org/

302-645-3300

Providing locations for walk in healthcare in southern Delaware

Christiana Care Health Services

www.christianacare.org/

302-733-1000

Major teaching hospital and one of the country's largest health care providers, located in Delaware

Nanticoke

Memorial Hospital

www.nanticoke.org/

302-337-9320

General medical and surgical hospital in Seaford, DE

Saint Francis Healthcare

www.stfrancishealthcare.org/

302-421-4100

Medical care and services throughout Wilmington, DE

Delaware Healthcare Facilities Association

www.dhcfa.org/

302-235-6895

non-profit organization of nearly 55 licensed health care facilities throughout Delaware

American Civil Liberties Union of Delaware

www.aclu-de.org/

302-654-3966

Local affiliate of the national ACLU, this group plays an important role in protecting the rights and liberties of Delawareans

Communtiy Legal Aid Society, Inc. of Delaware

www.declasi.org/

302-575-0660

Helps provide equal access to justice and legal services to qualifying Delaware residents

Aging and Disabilities Resource Center of DE

dhss.delaware.gov/dhss/dsaaped/index.html

800-223-9074

Advocates for, provides access to, and coordinates long-term services and supports in the most appropriate setting

Delaware Family Voices

www.delawarefamilytofamily.org/

302-669-3030

Supporting families of children with physical, developmental, and mental health issues by providing valuable resources and information

Delaware Elder Law Center

delawareelderlawcenter.com/

302-300-4390

Helping clients and their families in the areas of

medicaid planning, estate planning, will and trust planning, and more

Delaware Academy of Family Physicians

www.delfamdoc.org/

302-733-3356

Non-profit organization, and state chapter of the American Academy of Family Physicians, promoting excellence in healthcare and betterment of the health and people of Delaware

Delaware Academy of Medicine

www.delamed.org

302-733-3900

Non-profit organization striving to enhance the well-being of the community through education and the promotion of public health

Delaware Bar Association

www.dsba.org

302-658-5279

Professional organization uniting lawyers who practice in the State of Delaware

Delaware Nurses Association

www.denurses.org/

302-733-5880

Represents the interest of professional nurses in Delaware, advocating for health care issues, promoting the health of Delawareans, and establishing collaborative relationships throughout the state

Medical Society of Delaware

www.medsocdel.org/
302-366-1400
Society guiding, serving, and supporting Delaware physicians, promoting the practice and profession of medicine to enhance the health fo the communities

National Association of Social Workers, DE Chapter

naswde.org/index.php?bypassCookie=1
302-288-0931
Promotes, develops, and protects the practice of social work and social workers, and through its work and advocacy, seeks to enhance the effective functioning and well being of indiviuals, families, and communities in Delaware

Westside Family Healthcare

www.westsidehealth.org/
302-472-8632
Federally Qualified Health Center offering comprehensive, primary care medical home where patients are at the center of their care, primarily located in Wilmington, DE

Henrietta Johnson Medical Center

henriettajohnson.publishpath.com/
302-655-6187
Federally Qualified Health Center located in Wilmington, DE, and Claymont, DE offering a wide range of medical and dental services

La Red Health Center

www.laredhealthcenter.org/
302-855-1233
Federally Qualified Health Center located in Seaford, Milford, and Georgetown, offering quality patient care to the diverse members of the community

ARC of Delaware

www.thearcofdelaware.org/
302-996-9400
Promotes and protects the human rights of people with intellectual and developmental disabilities, and activiely supports full inclusion and participation in the communtiy through advocacy and services to individuals and their families

Delaware Center for Justice

www.dcjustice.org/
302-658-7174
Non-profit United Way Agency, dedicated to creating a safer, more secure Delaware by seeking to achieve and preserve a high quality of justice

Easter Seals of Delaware

www.easterseals.com/de/
302-324-4444
Offers a variety of services including medical rehabilitation services, employment and training, children’s services, adult and senior services, camping and recreation services

Mental Health Association of Delaware

www.mhainde.org/wp/
302-654-6833
The Mental Health Association in Delaware promotes improved mental well being for all individuals and families in Delaware through education, support, and advocacy

National Alliance of Mental Illness- Delaware

www.namidelaware.org/
302-427-0787
State chapter for the largest grassroots organization serving individuals living with mental illness and their families

Department of Justice Consumer Protection Unit

attorneygeneral.delaware.gov/fraud/cpu/
800-220-5424
The CPU is responsible for enforcing Delaware consumer protection statutes and protecting the general public from consumer frauds and scams.

Division of Developmental Disabilities Services

dhss.delaware.gov/ddds/
302-744-9600
Valuing persons with intellectual and developmental disabilities, honoring abilities, respecting choice, achieving possibilities and working together to support healthy, safe and fulfilling lives

Division of Services for Aging and Adults with Physical Disabilities

dhss.delaware.gov/dhss/dsaapd/index.html
800-223-9074
Advocates for, provides access to, and coordinates long-term services and supports in the most appropriate setting

Joining Generations

www.dhss.delaware.gov/dsaapd/jgserv.html
Is an intergenerational program operated by the Division of Services for Aging and Adults with Physical Disabilities. Joining Generations supports relative caregivers through advocacy, education, information, and other services

Division of Substance Abuse and Mental Health

dhss.delaware.gov/dsamh/
800-652-2929
To promote health and recovery by ensuring that Delawareans have access to quality prevention and treatment for mental health, substance use, and gambling conditions

Frequently Asked Questions:

Delaware Medical Orders for Scope of Treatment (DMOST)

DMOST is a process for documenting treatment choices. The DMOST form is voluntary. It is a portable, standardized Medical Order that will be recognized and followed by Delaware health care providers.

The DMOST conversation is an opportunity to understand the likely course of your health and medical condition, so that you may make informed choices that are appropriate and reflect what you want. If you choose, you may invite loved ones to join this conversation.

Q. What is DMOST?

A. The Delaware Medical Orders for Scope of Treatment (DMOST) form is a portable medical order form. It allows you to make choices about life-sustaining treatments, including among other treatments, CPR (resuscitation) and artificial nutrition. You may request full treatment, limited treatment, or comfort care only.

Q. Who is it for?

A. A DMOST form can be used by a person with a serious illness or frailty, whose health-care practitioner would not be surprised if they died within the next year.

Q. When should it be discussed and signed? Who signs it?

A. A DMOST form is completed after a conversation you have with a health care practitioner. It is signed by you and a physician (MD or DO), an advanced practice registered nurse (APRN), or a physician assistant (PA). The physician/APRN/PA signature makes the choices into portable medical orders.

Q. Who is required to follow the wishes documented on the DMOST form?

A. These orders will be followed by health care providers in any setting (ambulance, long-term care facility, emergency room, hospital, hospice, home, assisted living facility, etc.). It travels with you and is honored when you move to a new setting.

Q. Can someone else make DMOST decisions for me?

A. You make health-care decisions for yourself as long as you have decision-making capacity. You have the right to change your authorized representative at any time while you have decision-making capacity.

If a physician determines that a person lacks decision-making capacity, an authorized representative can sign a DMOST form on behalf of that person. A DMOST form does not change the decision-maker designated by an Advance Health Care Directive, a Health Care Power of Attorney document, a guardian of person appointed by a Court, or Delaware law on health care surrogates.

If you have capacity and complete a DMOST form, you can sign on the form saying that if you lose capacity, your authorized representative cannot void the form you signed.

Q. What if I change my mind?

A. If your condition or your choices change, you or your authorized representative should void (cancel) your DMOST form and request a new DMOST be completed with your new choices. You can void a DMOST form if you change your mind but do not want to create a new one. You may not make any changes to the content of the DMOST form. If you want to change your DMOST form you must void your previous form and complete a new one with your health-care practitioner. If your DMOST form does not agree with your advance directive, the most recent document will be followed.

Q. Must I do this?

A. The DMOST form is always voluntary and can be voided at any time. A Health care organization is prohibited from requiring you to complete a DMOST form for any reason, including as part of a person's admission to a health care facility.

It is important to understand that this form contains medical orders. It will be followed by health care providers. For example, if you choose "Do Not Attempt Resuscitation", and your heart stops, no attempt will be made to restart your heart. If you choose "Intubate/Use Artificial ventilation", then you may be placed on a breathing machine with a tube in your throat and transferred to an intensive care setting in a hospital.

Q. What will happen to my choices if I travel out of state?

A. Many states, including all the states in our region, currently use a form similar to the DMOST form. Forms from those states which are valid under the Delaware Law will be honored in Delaware. DMOST forms will be honored in other states which have reciprocity.

Delaware End-of-Life and Palliative Care Workgroup

Glossary of Terms

Advance Care Planning: Advance care planning is an ongoing process of discussing and clarifying the current state of a person's goals, values and preferences for future medical care. (HCM)

Advance Health Care Directive: an individual instruction or power of attorney for health care, or both. Advance directive is a general term referring to a written document to direct future medical care in the event that a person loses capacity to make health care decisions (i.e., becomes incapacitated). It sometimes results from the process known as advance care planning. A health care proxy or a living will is considered to be an advance directive. (DE/HCM)

Agent: an individual designated as power of attorney for health care to make a health care decisions for the individual granting the power.

AND or "Allow Natural Death" order: a term used at some hospitals as an alternative to the more traditional DNR order. While a DNR simply states that no attempts should be made to restart breathing or restart the heart if it stops, an AND order is used to ensure that only comfort measures, designed to provide excellent control of pain or other symptoms, are taken.

Artificial Nutrition And Hydration: supplying food and water through a conduit, such as a tube or intravenous line where the recipient is not required to chew or swallow voluntarily, including, but not limited to, nasogastric tubes, gastrostomies, jejunostomies and intravenous infusions. Artificial nutrition and hydration does not include assisted feeding, such as spoon or bottle-feeding.

Capacity: an individual's ability to understand the significant benefits, risks and alternatives to proposed health care and to make and communicate a health care decision.

Capacity can vary over time, and illness or medication can affect the person's capacity. If you are unsure whether a person has capacity to make health care decisions, you can ask a doctor or clinician to make a medical determination. (DE/HCM)

Cardiopulmonary Resuscitation (CPR): a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing. Such procedures may include the following:

- Pressing on the chest to mimic the heart's functions and cause blood to circulate
- Inserting an airway into the mouth and throat, or inserting a tube into the windpipe
- Ventilating artificially, through mouth-to-mouth or other mechanically assisted breathing
- Using drugs and/or electric shock (defibrillation) to stimulate the heart

CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness. (HCM)

Comfort Care: Comfort care is care that helps or soothes a person who is dying. The goal is to prevent or relieve suffering as much as possible while respecting the dying person's wishes. (DAM)

Comfort Care/Do Not Resuscitate Verification protocol (CC/DNR): followed by emergency medical service (EMS) personnel when encountering an authorized CC/DNR Verification Form outside of a hospital setting. The CC/DNR protocol directs that a patient in respiratory or cardiac arrest be made as comfortable as possible, but that no resuscitative measures be attempted. (HCM)

Conservator: a person (such as a family member or friend) or entity appointed by the court to manage the money, property, and business affairs of a disabled or incapacitated person. (HCM)

Conservatorship: a protective legal process in which the court may appoint a person called a Conservator. A Conservator's role is to marshal and manage the property of an individual who is disabled and who requires a substitute financial decision maker either to prevent the property from being wasted or dissipated, or so that the financial support, care, and welfare of the person is effectuated and managed. (HCM)

Continuum of Care: a concept involving a system that guides and tracks patients over time through a comprehensive array of health services spanning all levels and intensity of care. The Continuum of Care covers the delivery of healthcare over a period of time, and may refer to care provided from birth to end-of-life. (DAM)

Declarant: an individual who executes an advance health care directive.

Delaware Medical Orders for Scope of Treatment

(DMOST): a program designed to improve the quality of care Delaware residents receive at the end-of-life by translating patient/resident goals and preferences into medical orders. The full text of the recently passed DMOST legislation may be found at:

[http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/\\$file/legis.html?open](http://legis.delaware.gov/LIS/lis148.nsf/vwLegislation/HB+64/$file/legis.html?open)

Do Not Hospitalize orders (DNH): medical orders, signed by a physician, nurse practitioner or physician's assistant, to instruct health care providers not to transfer a patient from a setting such as a nursing facility (or the patient's home) to the hospital unless needed for comfort. (HCM)

Do Not Intubate orders (DNI): medical orders, signed by a physician, nurse practitioner, or physician's assistant that instruct health care providers not to attempt intubation or artificial ventilation in the event of respiratory distress. (HCM)

DNR (Do Not Resuscitate) orders: medical orders, signed by a physician, nurse practitioner, or physician's assistant that instruct health care providers not to attempt cardiopulmonary resuscitation (CPR) in the event of cardiac and respiratory arrest.

Durable Power of Attorney: a legal document in which you appoint a person you trust, called an Attorney-in fact, to manage your money, property and business matters if in the future you become disabled or incapacitated and are unable to manage your financial affairs yourself. A Durable Power of Attorney is usually created with the help of an attorney. A Durable Power of Attorney can avoid the need for Conservatorship. (HCM)

Electronic Record: a longitudinal record of patient health information generated by one or more encounters in any care delivery setting. (DAM)

Emergency Medical Services (EMS) Provider: individual providers certified by the Delaware State Fire Commission or the Office of Emergency Medical Services, within the Division of Public Health, Department of Health and Social Services or emergency certified medical dispatchers by the National Academy of Emergency Medical Dispatch.

Emergency Medical Services (EMS) Provider Agency: a provider agency certified by the Delaware State Fire Prevention Commission or the Office of Emergency Medical Services, or an emergency medical dispatch center under contract with the Department of Public Safety.

EMS Prehospital Advanced Care Directive Order (PACD): an advanced health care directive signed by the individual's physician on forms approved by the Director of the Division of Public Health. PACD is replaced by DMOST.

End-of-Life Decisions: decisions that require a range of questions including palliative care, patients' right to self-determination, medical experimentation, and ethics. These decisions don't refer only to patients in the final hours or days of their lives, but more broadly care of all those with a terminal illness or terminal disease condition that has become advanced, progressive and incurable. Ideally, end-of-life decisions respect the person's values and wishes while maintaining his or her comfort and dignity. (DAM)

Equity: the highest level of health for all people; this refers to efforts made to ensure that all people have full and equal access to opportunities that enable them to lead healthy lives. Patient Wishes. (DAM)

Guardian: a judicially appointed guardian or conservator having authority to make health care decisions for an individual.

Health Care: any care, treatment, service or procedure to maintain, diagnose or otherwise affect an individual's physical or mental condition.

Health Care Decision: a decision made by an individual or the individual's agent, surrogate or guardian regarding the individual's health care, including:

1. Selection and discharge of health care providers and institutions;
2. Acceptance or refusal of diagnostic tests, surgical procedures, programs of medication resuscitation; and
3. Directions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of health care.

Health Care Institution: an institution, facility or agency licensed, certified or otherwise authorized or permitted by law to provide health care in the ordinary course of business or practice of profession.

Health Care Proxy: a legal document in which you appoint a trusted person, called a Health Care Agent, to make health care decisions on your behalf if you become unable to make effective health care decisions for yourself. (HCM)

Hospice: a philosophy of holistic end-of-life care and a program model for delivering comprehensive palliative care to people who are in the final stages of terminal illness, and to their loved ones, in the home or a home-like setting. Hospice provides palliative care in the last months of life. It involves a team-oriented approach that is tailored to the specific physical, psychosocial and spiritual needs of the person and includes support to the family during the dying process. Hospice also provides bereavement support after death occurs. (HCM) In US, hospice is both philosophy of care and a Medicare benefit with clear requirements.

Individual Instruction: an individual's direction concerning a health-care decision for the individual.

Life-sustaining Procedure/Treatment:

1. Any medical procedure, treatment or intervention that:
 - a. Utilizes mechanical or other artificial means to sustain, restore, or supplant a spontaneous vital function; and b. Is of such a nature as to afford an individual no reasonable expectation of recovery from a terminal condition or permanent unconsciousness.
2. Procedures that can include, but are not limited to, assisted ventilation, renal dialysis, surgical procedures, blood transfusions and the administration of drugs, antibiotics and artificial nutrition and hydration.

Living Will: a personal document or statement in which a person specifies future medical treatments in the event of incapacity, usually at end-of-life or if one becomes permanently unconscious, in a persistent vegetative state or "beyond reasonable hope of recovery."

Mechanical Ventilation: In the healthcare setting or home, helps patients breathe by assisting the inhalation of oxygen into the lungs and the exhalation of carbon dioxide. Depending on the patient's condition, mechanical ventilation can help support or completely control breathing. (DAM)

Medical Orders for Life-Sustaining Treatment

("MOLST"): a specific order set for scope of medical treatment and provided on the MOLST form approved by the Division of Public Health. For State of DE it is a DMOST form. POLST and MOLST are designations for similar forms in other states.

Medically Ineffective Treatment: means that, to a reasonable degree of medical certainty, a medical procedure will not:

1. Prevent or reduce the deterioration of the health of an individual; or
2. Prevent the impending death of an individual.

Palliative care: a comprehensive approach to treating serious illness that focuses on the physical, psychosocial and spiritual needs of the patient. The goal of palliative care is to prevent and relieve suffering and to support the best quality of life for patients and their families through such

interventions as managing pain and other uncomfortable symptoms, assisting with difficult decision-making, and providing support, regardless of whether or not a patient chooses to continue curative, aggressive medical treatment. (HCM)

Patient Self-Determination Act of 1991: This legislation required many hospitals, nursing homes, home health agencies, hospice providers, health maintenance organizations (HMOs), and other health care institutions to provide information about advance health care directives to adult patients upon their admission to the healthcare facility. (DAM)

Permanent Unconsciousness: a medical condition that has existed for at least 4 weeks and that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, a persistent vegetative state or irreversible coma. This condition must be certified in writing in the patient's medical record by the attending physician and by at least 1 other physician who shall be a board-certified neurologist and/or neurosurgeon.

Personal Directive: a personal document or statement in which you give your Health Care Agent information and instructions about your values, preferences and choices for future medical care. A personal directive can be a personal letter or memo, and is also commonly known as an advance care directive, a living will, or medical directive. A personal directive is not legally binding but offers your health care agent essential information about the kind of care you want if you become incapacitated. (HCM)

Physician: an individual licensed to practice medicine under Chapter 17 of Title 24 of the Delaware Code.

Power Of Attorney For Health Care: the designation of an agent to make health care decisions for the individual granting the power.

Prehospital Advanced Care Directive (PACD): an EMS prehospital advanced care directive signed by the individual and the individual's physician, on forms approved by the Director of Public Health.

Primary Physician or Attending Physician: a physician designated by an individual or the individual's agent, surrogate or guardian to have primary responsibility for the individual's health care or, in the absence of a designation, or if the designated physician is not reasonably available, a physician who undertakes the responsibility for the individual's health care.

Supervising Health Care Provider or Health Care Provider: the primary physician, or if there is no primary physician or the primary physician is not reasonably available, the health care provider who has undertaken primary responsibility for an individual's health care.

Surrogate: an adult individual or individuals who (1) have capacity; (2) are reasonably available; (3) are willing to make health care decisions, including decisions to initiate, refuse to initiate, continue or discontinue the use of a life sustaining procedure on behalf of a patient who lacks capacity; and (4) are identified by the attending physician in accordance with 16 Del.C. §2507 as the person or persons who are to make those decisions.

Terminal Condition: any disease, illness or condition sustained by any human being for which there is no reasonable medical expectation of recovery and which, as a medical probability will result in the death of such human being regardless of the use or discontinuance of medical treatment implemented for the purpose of sustaining life or the life processes.

Withholding or Withdrawing Treatment: to stop life-sustaining treatments or discontinuing them after they have been used for a certain period. This is generally done when treatments are no longer helping to improve a patient's health, or the treatment is causing more symptoms. (TCP)

SOURCES

Title 16 HSS DE Administrative Code, Section 4304

DAM = Delaware Academy of Medicine (*original glossary*)

HCM = Honoring Choices Massachusetts

TCP = The Conversation Project

Delaware Receives Funding to Combat Chronic Disease



On behalf of the Delaware Coalition for Healthy Eating and Active Living (DE HEAL) the Delaware Chapter of the American Planning Association and the Delaware Academy of Medicine/ Delaware Public Health Association have received a \$135,000 grant from the American Planning Association through its Plan4Health program to combat two determinants of chronic disease—lack of physical activity and lack of access to nutritious foods. The funding for this national program is implemented in partnership between the American Planning Association and the American Public Health Association (APHA). This represents a major new collaboration between planners and public health professionals. Funding for Plan4Health was provided through an award from the Centers for Disease Control and Prevention (CDC).

“The funding provides fuel to address existing health concerns to create communities of lasting value that are equitable and healthy for all,” said Anna Ricklin, AICP, manager of APA’s Planning and Community Health Center, which manages the Plan4Health program. “We are very pleased to be working at both national and local levels with our colleagues in the American Planning Association. The intersection of planning and public health is an ideal place to focus our attention on effective change,” said Timothy Gibbs, MPH, executive director of the Delaware Academy of Medicine / Delaware Public Health Association.

The Delaware Coalition for Healthy Eating and Active Living seeks to change the approach in which comprehensive plans are updated to include considerations for health and equity. Using feedback from the community, the Coalition will create land use, design

and policy guidelines for planners and public health professionals seeking to improve the physical environment of where residents live, work and play in order to increase access to healthy food and build spaces that encourage active living.

Since comprehensive plan updates for the City of Dover and Kent County are scheduled for 2018/2019, the process in updating these plans will be underway by early 2017, coinciding with the Plan4Health grant period.

“Kent County is very excited about the opportunity to engage with the citizens of the County on how the built environment affects public health and identify potential policy changes that will improve the quality of life for our citizens,” said Mary Ellen Gray, AICP Assistant Director for Kent County Planning Service.

For more information about the Plan4Health program, visit www.plan4health.us or follow the hashtag #Plan4Health on Twitter. For the Delaware initiative, visit www.deplan4health.org or follow @deplan4health on Twitter.

The American Planning Association is an independent, not-for-profit educational organization that provides leadership in the development of vital communities. APA and its professional institute, the American Institute of Certified Planners, are dedicated to advancing the art, science and profession of good planning – physical, economic and social – so as to create communities that offer better choices for where and how people work and live. Members of APA help create communities of lasting value and encourage civic leaders, business interests and citizens to play a meaningful role in creating communities that enrich people's lives. APA has offices in Washington, D.C., and Chicago. For more information, visit www.planning.org.



American Planning Association
Delaware Chapter





The Delaware Health Care Commission recently established a workgroup to assess and make recommendations regarding End-of-Life and palliative care and related issues in Delaware. This workgroup has been charged with accomplishing a great deal over the next few months including the following:

- Reviewing relevant recommendations, reports, and other information in order to broaden the understanding of palliative care and end-of-life care issues and prioritize potential areas for recommendations.
- Identifying key end-of-life care issue areas, including advanced care planning.
- Developing recommendations and options for consideration regarding:
 - Consumer outreach, awareness and education activities regarding palliative and end-of-life care and planning, including advanced care planning and the recently enacted DMOST legislation;
 - Professional outreach, training, support and education concerning the care of those with serious chronic and life-threatening conditions;
 - Enabling access to palliative care services and supporting the capacity in the health care system to provide palliative care services in home, community, hospice, skilled nursing facilities, hospital and any other relevant settings;
 - Other recommendations to support comprehensive health care services to Delawareans suffering from advanced and serious illnesses.

As part of its initial efforts, the workgroup will develop and submit a report to the Delaware Health Care Commission providing recommendations and options on or before March 31, 2016. Included in the report will be a recommendation regarding the most appropriate framework for ongoing support and consideration of end-of-life issues in Delaware.

The timing of the convening of the workgroup and scope of its efforts are designed to build on recent developments and momentum at both the national and Delaware levels regarding end-of-life and palliative care. The workgroup members have been selected for their particular experience with this subject matter and include representatives from the public and private sectors, healthcare providers, community organizations, state agencies and the state legislature.

We invite broad public participation in the workgroup's efforts through multiple channels:

- All meetings are open to the public.
- Listening sessions will be held across Delaware in February to hear from community members about proposed initiatives.
- Comments and questions regarding the group's work may be sent to endoflife@choosehealthde.org.
- A **webpage** has been set up where meeting agendas, minutes and related materials will be posted. There is also a link to Delaware's public meeting calendar, where notices of upcoming meetings are posted.

Please consider attending a meeting or listening session or communicating through one of the above channels to add your perspective to this important discussion. We look forward to hearing from you.

LEGAL HANDBOOK FOR OLDER DELAWAREANS

Beginning April 1, 2016, DMOST, a new form of medical order, is available for patients whose health care practitioners would not be surprised if the patient died in the next year. The form is voluntary and cannot be required for admission to a health care facility. DMOST is a single document that will function as an actionable medical order and transition with a patient through all health care settings.

To create a DMOST, the patient (and if the patient desires, anyone the patient wishes to be present) will meet with a health care practitioner to discuss the patient's wishes for treatment and those wishes will be then documented on the DMOST form which is then signed by the health care practitioner and the patient. If the patient lacks decisional capacity, a legally authorized agent or guardian may meet with the health care practitioner to complete the DMOST form. The law requires any health care provider to honor the DMSOT form, if the patient is unable to communicate.

The DMOST is not intended to replace the Advance Health Care Directive but rather to supplement it, except that there is a section of the DMOST, which when signed by the patient, will limit the ability of an agent for health care to alter the DMOST.

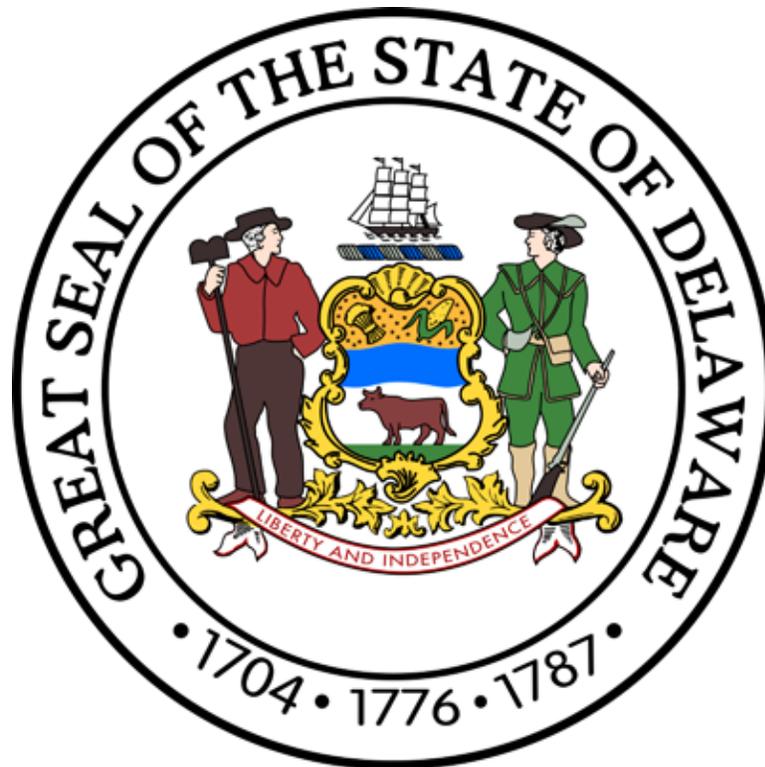
For more information concerning the DMOST, please [click here](#).

This handbook is hosted and maintained by the Elderlaw Section of the Delaware State Bar Association.

The process of passing legislation and writing regulations for DMOST was a monumental effort of many parties. Listening to and addressing community concerns, and carefully crafting the language upon which the actual DMOST form is based, is well reflected in the following regulations published in the January 1, 2016 Register.

Issue Date: January 1, 2016

**Volume 19 - Issue 7, Pages 637-641,
4304 Medical Orders for Life-Sustaining Treatment of Pre-Hospital Advance Care Directives**



Delaware Register of Regulations

DIVISION OF PUBLIC HEALTH

Statutory Authority: 16 Delaware Code, Chapter 25 (16 Del.C. Ch. 25)

16 DE Admin. Code 4304

ORDER**4304 Medical Orders for Life-Sustaining Treatment or Pre-Hospital Advance Care Directives****NATURE OF THE PROCEEDINGS:**

Delaware Health and Social Services (“DHSS”) initiated proceedings to adopt the State of Delaware Medical Orders for Scope of Treatment (4304). The DHSS proceedings to adopt regulations were initiated pursuant to 29 **Delaware Code** Chapter 101 and authority as prescribed by 16 Del.C. §2506A.

On November 1, 2015 (Volume 19, Issue 5), DHSS published in the Delaware Register of Regulations its notice of proposed regulations, pursuant to 29 **Delaware Code** Section 10115. It requested that written materials and suggestions from the public concerning the proposed regulations be delivered to DHSS by December, 2015, after which time the DHSS would review information, factual evidence and public comment to the said proposed regulations.

Written comments were received during the public comment period and evaluated. The results of that evaluation are summarized in the accompanying “Summary of Evidence.”

SUMMARY OF EVIDENCE

Minor comments regarding grammatical and formatting issues were received that addressed observations made throughout the document. These changes have been made in the final document presented here where the recommended change did not result in a substantive change to the meaning or intent of the section affected. Corrections to spelling, grammar and other technical aspects of the final regulations are not addressed individually here, but are highlighted in the final regulations published in the January edition of the Delaware Register.

Comments from State Council for Persons with Disabilities and the Governor’s Advisory Council for Exceptional Citizens

Comments on the proposed revisions to the DMOST Regulations were received from the Governor’s Advisory Council for Exceptional Citizen’s and the State Council for Persons With Disabilities. As the comments from both agencies were similar in scope and nature, they are addressed concurrently in this summary of evidence.

Comment:

First, in the definition of “Advance health care directive”, the definition seeks to clarify that Advance Health Care Directives (AHCDs) that are valid where executed are to be honored in Delaware. However, the regulatory definition adds the phrase “valid under Delaware law” to the statutory definition. This language suggests that the only out of state AHCDs that are recognized in Delaware are ones that are valid where executed and in Delaware. This requirement would prove unworkable and is inconsistent with the statutory language in 16 **Del. Code** §2503A(a) and of 16 **Del. Code** §2517, which plainly states that AHCDs valid where executed are honored in Delaware, whether they strictly comport to Delaware law or not.

Response:

The definition of Advance Health Care Directive has been revised for clarification that an AHCD is recognized in Delaware if it is recognized in the jurisdiction where it was executed.

Comment:

Second, Section 4.7 addresses situations where a person has decision-making capacity but is unable to communicate by speaking or writing. In those circumstances, the person is allowed to communicate through the method by which they usually communicate, so long as the person interpreting understands that method. This must be documented in the medical record. There is always a concern in these circumstances that the person interpreting is actually doing so and not substituting their own words or wishes. The requirement that there be a notation in the chart is a limited safeguard. However, it would be appropriate to add a requirement that there be a witness to this communication and that a health care practitioner has noted some indication of reliability regarding the ability of the interpreter to understand what is being communicated.

Response:

Additional documentation of the communication in these instances has been added to 4.7.2 to address these concerns.

Comment:

In addition, this section does not and cannot eliminate the requirement under the Americans with Disabilities Act (ADA) or state law that a health care facility provide effective communication for individuals with communication impairments. This should be clearly stated in the

regulation. It would be unfortunate for this regulation to be used to deny qualified interpreters when they are required and sanction the use of lay interpreters or family members, which is often inappropriate.

Response:

The existing requirement for facilities to provide effective communication to people with communication impairments is now stated in the regulation in 4.7.

SCPD and GACEC Comments on DMOST Form and Directions:**Comment:**

First, in the DMOST form, an "s" is needed in bullet 4 at the end of "measure."

Response:

Corrected.

Comment:

Second, in Section E, it is unclear who is signing on the line to the immediate right. You have to check the directions to be sure.

Response:

This has been addressed.

Comment:

Third, the line regarding whether an appointed representative can alter a DMOST should be set off in some fashion, either by bolding or by line. It gets lost in the rest of the box which is unfortunate since this is a very significant designation. The Division might consider using a yes/no box format or adding it to Box F.

Response:

An additional space has been added to help separate this line and make it clearer to the user of the form.

Comments from Stephen Kleiner, Esq., Kleiner & Kleiner, LLC**Comment:**

Ambiguities regarding revocation of Authorized Representative's authority to change or void the DMOST. Section E of the proposed DMOST form as shown in the proposed regulations, includes a line to provide the "Name of Authorized Representative," "Relation to Patient," "Address" and "Phone Number." Below that is a line stating, "[i]f lose capacity, my Authorized Representative may not change or void this DMOST," followed by a blank signature line identified as "Patient Signature."

From this form, it appears that the Division intends, pursuant to 16 **Del.C.** §2511A (c), that a patient may revoke a named authorized representative's authority to void or create a new DMOST only by expressly limiting such authority as evidenced by the patient's signature.

However, the proposed regulations at 2.1.2.5 state that "Section E contains ... a signature block for the patient to authorize an authorized representative the ability to void the DMOST form and execute a new DMOST form that changes the treatment choices if the patient loses decision-making capacity." (emphasis added) Contrary to the aforesaid form and 16 **Del.C.** §2511A (c), this language implies that such authority is, by default revoked, and the patient's signature is required to authorize such powers of an authorized representative. To avoid this ambiguity, I suggest that section 2.1.2.5 be changed to read as follows:

2.1.2.5 Section E contains information as to whom the DMOST form was discussed with and it contains a signature block allowing the patient to revoke an authorized representative's authority to void the DMOST form and execute a new DMOST form that changes the treatment choices if the patient loses decision-making capacity.

Response:

The section in question has been revised to address the concerns raised by this comment. The section has been revised for clarity to ensure the proper intent of the regulation is more evident.

Comment:

Authority to sign the DMOST under existing Advance Health-Care Directives ("AHCD") for an agent under 16 **Del. Code** Ch. 25. The proposed regulations at 4.9.1 state "[t]he health-care practitioner shall determine if there is an individual who is the patient's authorized representative. This is determined by referencing the documentation giving such individual the required authority under law. The documentation should establish both that the authorized representative is the person named in this role and that the authorized representative has the authority to sign the DMOST form on behalf of the patient." (emphasis added) Similar language appears at section 4.9.2.2 of the proposed regulations.

While 16 Del.C. §2503A (1) requires only that the authorized representative “has the authority to make decisions with respect to the patient’s health-care preferences being made on the DMOST form,” the proposed regulations may be construed so as to require an express grant of authority to actually sign the DMOST form.

Many individuals have previously executed a statutory AHCD as provided at 16 Del.C. §2505, or by using the form provided by the Delaware Department of Health and Social Services at <http://www.dhss.delaware.gov/dsaapd/files/advancedirective.pdf> (last visited November 11, 2015). Without modification, neither of these forms expressly grant the agent the “authority to sign the DMOST form on behalf of a patient.”

I suggest the language of the code be echoed in the proposed regulations, i.e. that the authorized representative have “the authority to make decisions with respect to the patient’s health-care preferences being made on the DMOST form.”

Response:

Clarifying language has been included in the final regulations.

Comments from Beverly Wik, Esq.

Comment:

Some of the edits of the attached forms are grammatical errors, others make sure that the same word is used consistently for the same thing in the same sentence or section of the proposed Regulations (as in patient, person, and individual in the same section or sentence), cap and not cap words that used repeatedly in the proposed Regulations are consistent, and inserting “articles” (such as an, a, the, etc.) in a sentence. Articles should be included but are often omitted in this day of texting and email-speak. I realize these are minor in nature, but I feel that the regulations should be grammatically correct.

Response:

Thank you for the thorough review of the proposed document. While we do not individually respond to these all the suggested edits, we have considered the recommendations and made the necessary edits in the final regulations. Responses to individual edits:

- AHCD Definition - Comments here were addressed by language revisions made in response to Mr. Kleiner’s comments.
- DMOST definition - This definition is taken largely from statutory language and only minor changes were made to existing text with one exception. The final statement was revised to read, The DMOST form is applicable across health-care settings, is reviewable, and [the patient controls if it] can be voided”. The revised language was used to clarify the patient has control over voiding the form.
- DMOST Form definition was revised to specify authorized representative in a case where a patient lacks decision making capacity.
- Patient’s Authorized Representative - comments on this section did not result in changes as the language used has been well-vetted with stakeholders and reviewers felt the existing statement was clear.
- Serious Illness or Frailty - comments on this section did not result in changes as the language used has been well-vetted with stakeholders and reviewers felt the existing statement was clear.
- 2.1 - Comments suggesting “a form” be used did not result in revision. DHSS feels that adding the article would indicate that it is permissible to use any form, rather than the DHSS form that is required.
- 2.1.2.3.2 - Location is used as this language was carefully vetted and it refers to where the patient is. Setting could mean a different location but the same level of care.
- 3.1.6 - The proposed language was retained because it covers a broader scope of possible scenarios.
- 4.6 - comments on this section did not result in changes as the language used has been well-vetted with stakeholders and reviewers felt the existing statement was clear.
- 4.9 - comments on this section did not result in changes as the language used has been well-vetted with stakeholders and reviewers felt the existing statement was clear and the comment is further addressed by language added in 4.9.1
- 4.9.2 - comments on this section were addressed by changes to 4.9.1.
- 4.9.2.1 - comment on this section did not result in revisions as the language was well-vetted with stake holders and provides flexibility of language in considering an order from another jurisdiction.
- 4.10 - Language revised to address comment.
- 5.4 - Language revised to address comment.
- 8.3 - Comments on this section did not result in revisions as the language is well-vetted with stakeholders and DHSS feels it is adequate.

Comment:

One pervasive problem is not using the hyphen in health care when “health care” is used as an adjective. When “health care” is used as an adjective it includes a hyphen and the DE Code for Advance Health-Care Directives consistently uses health-care when followed by Directive or “institution.” When “health care” is used as a noun, then there is no hyphen, as in “the nurse provides health care to patients in the hospital.”

Response:

After discussion within the Division of Public Health and review of the spelling and format of health care in statutes and other references, changes were made throughout these regulations. The final document consistently uses the accepted form, "health care" except when referring to "Advance Health-Care Directive" because that is the name of the legal document as stated in the statute.

Comment:

Lastly, I am concerned about Reg subsection 4.9.2 on page 5 of the attached. That subsection repeatedly uses the phrase "only with the appropriate authority." I strongly feel that this phrase should be given some explanation and tied to the documentation giving a patient's authorized representative the required authority under law. Healthcare practitioners may not understand what is required and what the committee intended in its lengthy discussions about the authority of authorized representatives. I fear that health-care providers may assume that all that needs to be evaluated is whether a person is the appointed representative having the highest priority.

Because such evaluation is only the first step in the evaluation of the authority of a patient's authorized representative, I suggest adding a subsection 4.9.3 that explains the second step of such evaluation, i.e., understanding what is meant by "with the appropriate authority." Below is a suggested additional subsection to follow subsection 4.9.2.

4.9.3 If an authorized representative is executing a DMOST form for a patient without decisionmaking capacity that directs that life-sustaining treatment be withheld or withdrawn from such patient, the documentation relied upon by the health-care practitioner to determine the authorized representative's authority should indicate that the authorized representative has the authority to make the specific decisions that such authorized representative is indicating on a DMOST form, specifically decisions that direct that life-sustaining treatment be withheld or withdrawn. This is required because an order appointing a guardian of the person may not authorize that life-sustaining treatment be withdrawn or withheld (this is authority that is not part of a guardian of the person's general authority unless indicated in the court order appointing the guardian or a further order addressing the administration of life-sustaining authority), a medical power of attorney may not authorize withholding or withdrawing life-sustaining treatments, or only authorize withdrawing or withholding of life-sustaining treatment, until there has been a determination that the patient has certain conditions that physicians must certify (that a patient is in a permanently unconscious state or is in a terminal state), and a surrogate under the Delaware Surrogate Statute does not have the authority to authorize withholding or withdrawing life-sustaining treatments unless again the patient has certain conditions that physicians must certify (is in a permanently unconscious state or is in a terminal state). In such instances, even if a DMOST form is signed by an authorized representative, the authorized representative will not have the "appropriate authority." Then action taken by healthcare providers that rely upon a DMOST form signed by an authorized representative of a patient who does not have the appropriate authority could expose the authorized representative and the health-care providers to liability for improperly withholding or withdrawing life-sustaining treatment from a patient. In the event that a health-care practitioner is unsure as to whether an authorized representative has the appropriate authority, he or she should confirm the authority with the legal authorities of the patient and/or the authorized representative.

Response:

This comment is addressed by the change made to 4.9.1 in response to a similar comment from Mr. Kleiner.

FINDINGS OF FACT:

Minor changes were made to the proposed regulations based on the comments received. The Department finds that the proposed regulations, as set forth in the attached copy should be adopted in the best interest of the general public of the State of Delaware.

THEREFORE, IT IS ORDERED, that the proposed State of Delaware Medical Orders for Scope of Treatment (4304) is adopted and shall become effective April 1, 2016, after publication of the final regulation in the Delaware Register of Regulations.

Rita M. Landgraf, Secretary

***Please Note: Due to the size of the final regulation, it is not being published here. A copy of the regulation is available at:**

[4304 Medical Orders for Life-Sustaining Treatment or Pre-Hospital Advance Care Directives](#)

HELP SHAPE END-OF-LIFE CARE IN DELAWARE.

Please join the discussion about palliative care, hospice care, advance care planning, and related issues.

Delaware has the opportunity to enhance the quality of life for people with advanced or serious illnesses. **You can be part of the experience** by participating in public listening sessions and sharing your thoughts about palliative care and end-of-life care issues.

Please attend one of the following sessions to voice your thoughts and ideas.

Dover: Monday, February 1, 2-4 p.m.

Division of Public Health Training Room at Edgehill Shopping Center, 43 S. Dupont Highway
DART Accessibility: Route 108: Division Street and CVS Stop (0.1 miles away)

Lewes: Tuesday, February 2, 12-2 p.m.

Lewes Public Library, 111 Adams Avenue
DART Accessibility: Route 206: Savannah Road and Beebe Avenue (0.3 miles away)

Seaford: Tuesday, February 2, 5-7 p.m.

Seaford Public Library, 600 N. Market Street Extension
DART Accessibility: Route 212: Front Street at Mill Street Stop (0.4 miles away) and Route 212: Front Street at Walker Street Stop (0.4 miles away)

Newark: Wednesday, February 3, 6-8 p.m.

STAR Campus Atrium, University of Delaware, 550 S. College Avenue
DART Accessibility: S. College Avenue and North Chrysler Entrance (Routes 16, 33, 39, 46) and Newark Train Station: Route 59 (0.3 miles away)

For more information about the Delaware Health Care Commission's End-of-Life Workgroup, visit <http://dhss.delaware.gov/dhss/dhcc/endoflife.html>

The DMOST form will be available for use on **April 1, 2016**. The following draft watermarked version **MAY NOT BE USED** and is provided for information **ONLY**. The Goals of Care Delaware program of the Delaware Academy of Medicine will be coordinating the implementation and training efforts around DMOST with a dedicated team of professionals from across the healthcare and legal sectors led by John Goodill, MD. The Medical Society of Delaware and the Delaware Academy of Family Physicians will play an integral role, and we are grateful for their participation and support. Training for use of the DMOST form will come in multiple formats including online web-based training and live education sessions throughout the State. Please refer to www.d-most.org for additional information in March 2016.

DELAWARE MEDICAL ORDERS FOR SCOPE OF TREATMENT (DMOST)

- FIRST, follow the orders below. THEN contact physician/or other health-care practitioner for further orders, if indicated.
- The DMOST form is voluntary and is to be used by patient with serious illness or frailty whose practitioner would not be surprised if they died by next year.
- Any section not completed requires providing the patient with the full treatment described in that section.
- Always provide comfort measure, regardless of the level of treatment chosen.
- The Patient or the Authorized Representative has been given a plain-language explanation of the DMOST form.
- The DMOST form must accompany the patient at all times. It is valid in every health care setting in Delaware.

Print Patient's Name (last, first, middle)		Date of Birth	last four digits of SSN
A	Goals of Care (see reverse for instructions. This section does not constitute a medical order.)		
B	Cardiopulmonary Resuscitation (CPR) <i>Patient has no pulse and/or is not breathing</i> <input type="checkbox"/> Attempt resuscitation/CPR. <input type="checkbox"/> Do not attempt resuscitation/DNAR.		
C	Medical Interventions: <i>Patient is breathing and/or has a pulse.</i> <input type="checkbox"/> Full Treatment: Use all appropriate medical and surgical interventions, including intubation and mechanical ventilation in an intensive care setting, if indicated to support life. Transfer to a hospital, if necessary. <input type="checkbox"/> Limited Treatment: Use appropriate medical treatment, such as antibiotics and IV fluids, as indicated. May use oxygen and noninvasive positive airway pressure. Generally avoid intensive care. <input type="checkbox"/> Transfer to hospital for medical interventions. <input type="checkbox"/> Transfer to hospital only if comfort needs cannot be met in current setting. <input type="checkbox"/> Treatment of Symptoms Only/Comfort Measures: Use any medications, including pain medication, by any route, positioning, wound care, and other measures to keep clean, warm, dry, and comfortable. Use oxygen, suctioning, and manual treatment of airway obstruction as needed for comfort. Use antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current setting. <input type="checkbox"/> Other Orders: _____)		
D	Artificially Administered Fluids and Nutrition: <i>Always offer food/fluids by mouth if feasible and desired.</i> <input type="checkbox"/> Long-term artificial nutrition <input type="checkbox"/> Defined trial period of artificial nutrition: Length of trial: _____ Goal: _____ <input type="checkbox"/> No artificial nutrition <input type="checkbox"/> hydration only <input type="checkbox"/> none (check one box)		
E	Orders Discussed With: <input type="checkbox"/> Patient _____ ph.# _____ <input type="checkbox"/> Guardian <input type="checkbox"/> Surrogate (per DE Surrogacy Statute) Printed Name & phone number <input type="checkbox"/> Other <input type="checkbox"/> Agent under healthcare POA/or AHCD _____ <input type="checkbox"/> Parent of a minor Signature _____ Print Name of Authorized Representative Relation to Patient Address Phone # If I lose capacity, my Authorized Representative may not change or void this DMOST _____ Patient Signature		

F	SIGNATURES: Patient/Authorized Representative/Parent (mandatory) <i>I have discussed this information with my Physician / APRN / PA</i>	Physician / APRN / PA	
	<hr/> Signature _____ Date _____	Signature _____	Date _____
	If authorized representative signs, the medical record must document that a physician has determined the patient's incapacity & the authorized representative's authority, in accordance with DE law.	<hr/> Print Name _____	
		<hr/> Print Address _____	
		License Number _____	Phone # _____

DIRECTIONS FOR HEALTH-CARE PROFESSIONALS

COMPLETING A DMOST FORM

- Must be signed by a Licensed Physician, Advance Practice Registered Nurse or Physician's Assistant.
- Use of original form is highly encouraged. Photocopies and faxes of signed DMOST forms are legal and valid.
- Any incomplete section of a DMOST form indicates the patient should get the full treatment described in that section.

REVIEWING A DMOST FORM -- It is recommended that a DMOST form be reviewed periodically, especially when:

- The patient is transferred from one care setting or care level to another,
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

MODIFYING AND VOIDING INFORMATION ON A COMPLETED DMOST FORM

A patient with decision-making capacity can void a DMOST form at any time in any manner that indicates an intent to void.

Any modification to the form voids the DMOST form. A new form may be completed with a healthcare practitioner.

Forms are available online at www.delaware.gov/

SECTION A This section outlines the specific goals that the patient is trying to achieve by this treatment plan. Healthcare professionals shall share information regarding prognosis with the patient in order to assist the patient in setting achievable goals. Examples may include:

- Longevity, cure, remission or better quality of life
- To live long enough to attend an important event (wedding, birthday, graduation)
- To live without pain, nausea, shortness of breath or other symptoms
- Eating, driving, gardening, enjoying time with family, or other activities

SECTION B This is a medical order. Mark a selection for the patient's preferences regarding CPR.

SECTION C This is a medical order. When "limited treatment" is selected, also indicate whether the patient prefers or does not prefer transfer to a hospital for additional care.

- IV medication to enhance comfort may be appropriate treatment for a patient who has indicated "symptom treatment only"
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP) and bi-level positive airway pressure (Bi-PAP).
- The patient will always be provided with comfort measures.
- Patients who are already receiving long-term mechanical ventilation may indicate treatment limitations on the "Other Orders" line.

SECTION D This is medical order. Mark a selection for the patient's preferences regarding nutrition and hydration. Check one box.

- Oral fluids and nutrition should always be offered if feasible and consistent with the goals of care.

SECTION E This section documents with whom the medical orders were discussed, the name of any healthcare professional who assisted in the completion of the form, the name of any authorized representative and whether the authorized representative may not modify/void the form.

SECTION F To be valid, all information in this section must be completed.

HIPAA PERMITS DISCLOSURE OF DMOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT.

SEND FORM WITH PATIENT WHENEVER MOVED TO A NEW SETTING
Faxed, Copied, or Electronic Versions of the Form are legal and valid.

'State of Public Health 2016'

with CDC Director Tom Frieden

by Daniel Greenberg



In his fourth annual "state of public health" address for Public Health Newswire, CDC Director Tom Frieden discusses topics from the past and current year, including climate change, prescription drug overdose and antibiotic resistance. Photo by CDC

Every year, Centers for Disease Control and Prevention Director Tom Frieden rings in the new year with his "State of Public Health" address right here on APHA's Public Health Newswire. His fourth annual update to the public health community worldwide once again recaps the biggest stories of 2015 and lets us know our greatest challenges and opportunities in 2016, from climate change to prescription drug overdose to antibiotic resistance — and much, much more.

One week before the president's State of the Union address hits the airwaves, we're proud to bring you the "State of Public Health 2016" with Dr. Frieden. Enjoy!

Q: What are CDC's greatest opportunities and challenges for 2016?

A: CDC and our state, tribal, local and global partners have enormous challenges in the coming year.

- We need to completely extinguish Ebola in West Africa, eradicate polio in Pakistan and Afghanistan, and accelerate the work of strengthening public health infrastructure in every country so that the world will be better protected from the next threat.
- We must find and stop outbreaks of drug-resistant organisms rapidly and protect antibiotics by greatly improving their rational use among both humans and feed animals.

- We have to reverse the tragic and devastating opioid epidemic, particularly through improved prescribing practices for pain and addiction, and working with law enforcement to reduce the supply (and thus increase the cost) of illicit opioids.
- We have to double down on efforts to prevent our two leading killers – cardiovascular disease and cancer – by intensifying implementation of comprehensive tobacco control and making even more progress in our Million Hearts campaign.

We are under pressure to keep effective programs from becoming victims of their own success. As public health historian John Duffy noted: "Encountering apathy, ignorance, and avarice is the lot of all conscientious health officers. As preventive measures in the health area are more successful, the public is less inclined to support the programs which ensure this success."

Thanks to the Tips from Former Smokers campaign and other tobacco control efforts, for example, fewer Americans smoke than ever before. Unfortunately, this success has led to complacency. Funding for the Tips campaign is threatened, even though it is an extremely cost-effective program that saves at least 16,000 lives each year.

Even the most successful public health programs require constant evaluation, innovation, and improvement. The progress we achieve builds on itself to create new opportunities to improve the nation's health and reduce disparities.

Q: Last year's CDC budget increased activities to prevent and combat antibiotic resistance, prescription drug overdose, global health security and laboratory safety and quality. How has CDC bolstered its attention to each of these concerns?

A: Antibiotic resistance may be the single most important infectious disease threat of our time. But we can delay, and

sometimes even reverse, the spread of antibiotic resistance by becoming better stewards of these essential life-saving medications. Last June, the Administration proposed critically needed investments for an aggressive, coordinated approach that — if implemented — could prevent thousands of antibiotic-resistant infections and deaths and save billions of dollars in medical costs.

Last year, prescription opioid overdoses killed nearly 19,000 Americans, an increase of 16 percent in just one year. CDC supports states to optimize prescription-drug monitoring programs, take advantage of new Medicaid- and insurer-benefit strategies, and develop policies to improve clinical practice. Our FY2014 pilot program helped five states fight prescription drug overdose and is now set to expand to all 50 states. New opioid prescribing guidelines will help doctors and patients balance the substantial risks of addiction and death with the unproven benefits for chronic, non-cancer pain and increase availability and use of safer and equally effective treatment options.

Global health security protects Americans' health by stopping diseases abroad so we don't have to stop them here. Over the next five years, we and our more than 50 international partners will provide at least 30 nations — home to more than 4 billion people — with the tools they need to prevent avoidable epidemics, detect outbreaks early, and respond rapidly to disease threats before they spread.

The goal of all CDC laboratory programs is to keep America healthy, safe, and secure using the highest quality science. We strive to be the safest laboratories anywhere, and are fortunate to have one of the world's leading laboratory experts, Dr. Steve Monroe, as our new Associate Director for Laboratory Science and Safety. We have already made progress making our labs the model for scientific excellence and safety.

Q: Thanks in large part to CDC's largest and most intensive response in its history, the year saw the epidemic end in Sierra Leone and Liberia, but as you told us last year, "Our goal isn't just to get to zero, but to stay at zero." How are CDC and global health workers doing in this regard, and how close are we to seeing no cases worldwide?

A: By the time this is published in early January, all of West Africa may well be free of Ebola virus transmission according

to World Health Organization standards. But that doesn't mean our mission is over. We've helped establish systems in Guinea, Liberia, and Sierra Leone to rapidly detect and respond to any new Ebola outbreaks. Many CDC experts continue to be deployed to the region to strengthen local capacity and put an end to the worst Ebola epidemic in history, and our new offices in these countries will work to strengthen public health capacity to stop many health threats.

Q: The World Health Organization has said that climate change is the greatest threat to global health in the 21st century. What do you feel is the appropriate public health response moving forward?

A: CDC's Climate and Health program has worked for many years to help states prepare for specific health impacts of climate change such as increased air pollution, extremes in weather, and faster spread of food and waterborne diseases. CDC scientists warned the nation of the increased threat of vector-borne diseases, such as dengue and chikungunya, which are now seen in areas they were never present before. CDC's Building Resilience Against Climate Effects (BRACE) framework is helping health officials prepare for climate change, and our Climate Ready States and Cities Initiative is funding 16 states and two cities to identify likely climate impacts and associated health threats.

Q: This year APHA launched its Generation Public Health campaign to include everyone and everything that impacts health — from housing, education and income to community design, transportation and our environment. How can CDC, APHA and our peers in public health tap into these sectors to create the healthiest nation in one generation?

A: Generation Public Health builds on a key concept: every aspect of business, government, education, and communication involves health at some level. Partnerships with diverse sectors — when done openly and adhering to scientific principles — can result in effective, evidence-based programs that improve health. A "health in all policies" approach recognizes this interconnectedness and the synergies that can be achieved when all segments of society work together. ■

From the History and Archives Collection

The Delaware Academy of Medicine has a number of books in its historical collection which pertain directly to death and dying, and countless others which provide a window to how end of life has been perceived through the ages.

According to the Hospice Education Institute:

"Each society throughout history has evolved special ways of caring for the dying and the bereaved. For example: in old China the "death houses" offered a place for the destitute dying to stay; in New Zealand, Maori customs give practical support for the family at the time of death, and encourage the community to participate in the mourning rituals; in East Africa, wise elders give both practical and spiritual support to the dying and bereaved."

They go onto state:

"(in the) Middle Ages: Religious orders establish "hospices" at key crossroads on the way to religious shrines like Santiago de Compostela, Chartres and Rome. These shelters helped pilgrims, many of whom were traveling to these shrines seeking miraculous cure of chronic and fatal illnesses, and many of whom died while on their pilgrimages."

An excerpt from a book in our collection, "History of Medicine" by Fielding H. Garrison, A.B., M.D., F.A.C.S. donated by the family of Edwin Bird, M.D., one of the founding trustees of the Academy, is show below. It references hospices directly, and the plan of Saint Gall, a monastic compound dating from the early 9th century which would include a "hospital, with a room for grave cases."

"The ideal plan of St. Gall (820) included a hospital, with a room for grave cases, dwelling-houses for physicians, bath-rooms for cupping and bleeding, and a pharmacy."

